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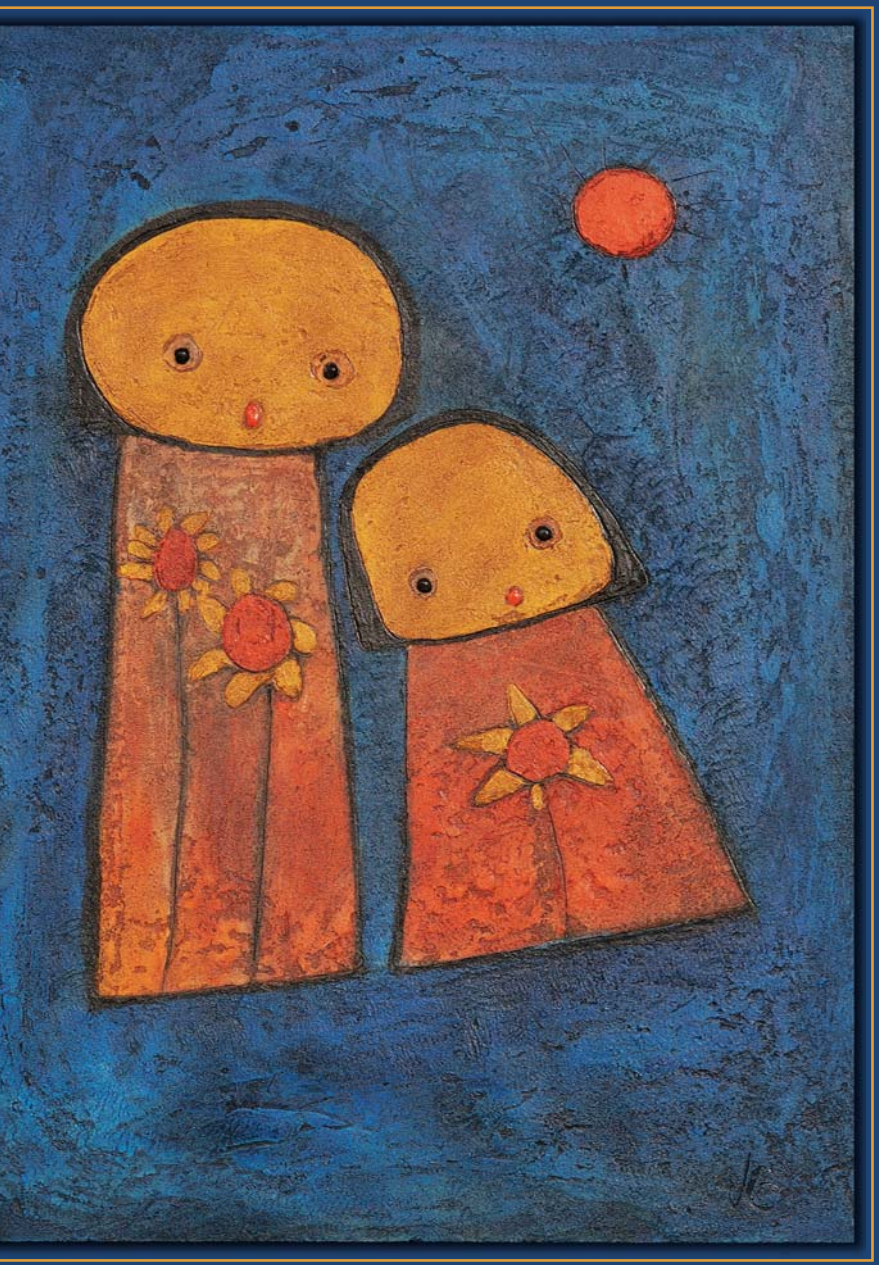

Stakeholders' Influences in Community-Based Rehabilitation

Harry Finkenflügel

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Die Gesichter, die dem Betrachter wahrhaft “entgegenkommen”, nehmen direkten Blickcontact mit ihm auf. Dieser Blickcontakt ist zentraler Inhalt der Arbeiten einerseits, und macht es anderenseits fast unmöglich, sie einer distanzierten Analyse zu unterwerfen. Die Einbildung fuktioniert so unmittelbar, dass es oft recht schwierig oder auch befremdlich erscheint, mit diesen Blicken, “einfach” umzugehen.

The faces that are coming towards the observer are taking up direct visual contact with him. This visual contact is - on one hand - the central content of his works and on the other hand makes it impossible to analyse them at a distance. The imagination is working immediately making it often very hard or disconcerting to handle these looks “easily”.

(text in German: Christine Glenewinkel in: I Colori della vita. Die Farben des Lebens. Giovanni Vetere wird 60, English translation by Monika Hoffman)

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Preface

Fifteen years ago, in September 1988, I arrived in Zimbabwe to take up a position as a teacher at the Rehabilitation Assistants Training School in Harare. In my first week Mrs. S. Chidyausiku, head of the Rehabilitation Unit in the Ministry of Health, asked me to represent the school in the committee set up to monitor the Community-based rehabilitation (CBR) pilot projects in Zimbabwe.

CBR was a challenge in many ways. Zimbabwe had rapidly decentralised its health services and adopted the Primary Health Care approach. Supported by donor organisations, the Ministry of Health was determined to improve the care for people with disabilities along the same lines. One of the challenges was to train the cadres for CBR. From 1981 'Rehabilitation Assistants' have been trained in Zimbabwe and in 1988 the University of Zimbabwe started a physiotherapy and occupational therapy training. At that time most therapists working for the Ministry of Health were expatriates. Both expatriates and the people trained in Zimbabwe were educated in the Western medical tradition and their skills and experience in counselling and training people with disabilities, their families, and volunteers in disadvantaged communities were limited. A second challenge was to beat the scepticism of many professional rehabilitation workers. Their fear of 'watering down' services and expertise and offering 'second-rate' services to people who were, in their view, entitled to 'the best' was difficult to address. Apart from the WHO manual and the book "Disabled Village Children" we had no documentation and evidence available to show that lay people and semi-skilled rehabilitation workers could provide adequate assistance. The few CBR projects already running in Zimbabwe had too many problems to convince the more reluctant rehabilitation workers. Most decisive in the process was that there were indeed enough rehabilitation workers to take up the challenge and to start projects. These projects were generally well prepared and problems were solved when they arose. Although I personally was in favour of this naïve approach I was also worried about the accountability of the efforts made and asked the Rehabilitation Technicians to collect specific data on the projects, the volunteers, and the people with disabilities involved in the projects. I also started reading on CBR as much as I could get my hands on. The early correspondence with M. Miles, Brian O'Toole and Marigold Thorburn motivated me to get even more involved in CBR.

In 1991 the eight pilot projects were well underway and my contract ended. I returned to The Netherlands with a fascination for CBR. Dr. Adri Vermeer and prof. dr. Brian Hopkins of the Vrije Universiteit motivated me to set up a curriculum and to get students involved in rehabilitation in developing countries. Together with prof. dr. Ivan Wolffers I edited a book "The handicapped community" and this was published in 1993. Since then, the idea of writing a Ph.D. thesis stayed with me. In the ten years that it took me to write a consistent study on CBR many events have sidetracked me from this thesis but the simple fact that this book is now on your desk means that I'm really convinced that CBR is still an interesting approach.

Glossary

CBR	Community-Based Rehabilitation
CRW	Community Rehabilitation Worker
CW	Community Worker
IBR	Institution-Based Rehabilitation
ILO	International Labour Organisation
ILS	Intermediate Local Supervisor
LS	Local Supervisor
NGO	Non-Governmental Organisation
PHC	Primary Health Care
RA	Rehabilitation Assistant
RCV	Red Cross Volunteer
RT	Rehabilitation Technician
SIDA	Swedish International Development Authority
UN	United Nations
UNDP	United Nations Development Programme
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNICEF	United Nations Children's Fund
VCW	Village Community Worker
VHW	Village Health Worker
WHO	World Health Organization

About the use of he, she, his, her, ...

Community-based rehabilitation has sometimes been referred to as Mother-Based Rehabilitation to illustrate that it is usually the mothers, grandmothers, aunts and sisters that care for people with disabilities. It is also observed that most of the volunteers are women. Men are better represented in the professional cadres while the rehabilitation workers at district and provincial level are mostly women. It is for these reasons that in this thesis 'she' and 'her' have been consequently used. As such the probably more correct but unattractive 'he/she' and 'his/her' is avoided.

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Uncovering Community-based rehabilitation (CBR)

1

Abstract

Twenty-five years of Community-based rehabilitation (CBR) have enriched the field of rehabilitation with numerous rehabilitation programmes for people with disabilities in rural and urban areas in developing countries. CBR has been presented as an alternative or complementary approach to rehabilitation in institutions. In developing countries, these institutions were non-existent, or considered inadequate. In the CBR concept, rehabilitation of people with disabilities takes place in the community and relies explicitly on the involvement of lay people, i.e. family members, volunteers, schoolteachers and village community workers.

Despite the ample experience gained with CBR and the evaluations and research studies that have been carried out, the concept and the effectiveness of CBR is still being questioned. This thesis discusses the 'state of the art' of CBR and analyses the findings, pitfalls and shortcomings of current research in CBR, i.e. regarding the competencies and influences of stakeholders involved. It is expected that this approach will contribute to a better conceptualisation of CBR, with the potential to enhance the further development of CBR.

In this chapter, definitions of the concepts used in this thesis and the research questions are presented with a brief introduction to the chapters, in which these questions will be answered.

1.1 Introduction

The (unpublished) WHO report "Disability prevention and rehabilitation" (WHO, 1976) can be taken as the starting point of CBR. CBR was presented as a new and promising approach to provide rehabilitation services to people with disabilities in developing countries. In a resolution the WHO recommended the provision of essential services and training for the disabled through Community-based rehabilitation (CBR), especially in developing countries (WHO, 1976 in: WHO, 1982 page 3). In 1981, the WHO Expert Committee on Disability Prevention and Rehabilitation published a document on CBR with the same title as the one put out in 1976 (WHO, 1981). In this report the following definition of CBR was given:

> *"Community-based rehabilitation involves measures taken at the community level to use and build on the resources of the community, including the impaired, disabled, and handicapped persons themselves, their families, and their community as a whole."*

According to the WHO report, 10% of the world's population has disabilities and this causes serious social, economic, physical, and psychological problems not only for the person with a disability and her/his family but also for their communities and society. The assumption was made that at any time 1.5% of the population could benefit from rehabilitation and *"...thus 40 million disabled people in developing countries need rehabilitation"* (WHO, 1981 pages 10,11). The Expert Committee also emphasised that surveys showed that the quality of life of people with disabilities was low compared to other people in the same community. They mentioned that people with disabilities are more likely to suffer from poverty, are sick more often, have less opportunity to go to school or find a job, are excluded from a position of leadership, are often segregated, and suffer from negative attitudes and discriminatory behaviour. In addition, the effectiveness, impact, and coverage of institutions providing rehabilitation services in developing countries were heavily criticised. The main points of criticism were that these institutions are situated in towns and were practically inaccessible to people with disabilities

living in rural areas, are often run by non-governmental organisations, are dependent on expatriate staff, and were not integrated with other health or social services.
The real move forward for CBR came with the active and wide distribution of the manual "Training Disabled People in the Community" (Helander, Mendis, & Nelson, 1983) to policy makers and rehabilitation workers in developing countries. This manual was based on the preceding experimental manuals published in 1997 and 1980 (Helander, Mendis, & Nelson, 1980) and consisted of 32 training packages to be used by a family member of a person with a disability and separate guides for local supervisors, community leaders and schoolteachers. In these packages emphasis was given to problems experienced in activities of daily living and not to the underlying pathology or the medical condition. The basic idea of this manual was that the rehabilitation process can be broken down into steps-to-follow and can be explained to people without a professional background in rehabilitation, special education, vocational training, etc. Training packages consisted of a series of exercises that should be carried out by family members and volunteers with the person with a disability. The manual did not provide a theoretical background on the principles of CBR. In fact, not even a definition of CBR was given. In a short introduction the authors stated that CBR is a new approach whereby *"the families are given the responsibility of training their disabled members and assisting with self-training"*.
At a first evaluation of nine CBR pilot projects, the emphasis was again on the high proportion of people with disabilities (7-10%) with hardly any rehabilitation services available (98% of people with disabilities had no access to services), the low socio-economic status, victimisation by superstition and beliefs, and social isolation (WHO, 1982). According to the report *"CBR aims at giving the disabled the necessary training, providing them with education and jobs, involving them in normal family and community life and restoring their dignity"*. It was concluded that CBR, supported by the manual, had proven to be an appropriate approach to provide rehabilitation to people with disabilities in developing countries. According to the conference report *"its training techniques have been proven to be effective and its results equal to those of IBR"*.
In the CBR evaluation report (WHO 1982) general principles underlying the CBR concept were given.
It was stated that the CBR approach:
– promotes awareness, self reliance and responsibility for rehabilitation in the community;
– builds on manpower resources in the community, including the disabled themselves, their families and other community members;
– encourages the use of simple methods and techniques which are acceptable, affordable, effective and appropriate to the local setting;
– uses the existing local organisation and infrastructure to deliver services, especially primary health care services; and
– takes into consideration the economic resources of the country and thus allows for an eventual extension to provide total coverage according to perceived needs.

In addition to the manual "Training the disabled in the community" separate guides were compiled for managers and trainers/supervisors (intermediate-level supervisors) of CBR programmes. In the guide for intermediate-level supervisors (Mendis & Nelson, 1983), rehabilitation was defined as *"the process which results in giving disabled people the opportunity to*

participate as members of their families and communities and societies as a whole". This definition stressed the idea of equal opportunities and brought disability and rehabilitation into a local and cultural context. According to the authors of this guide, rehabilitation must (1) enable disabled people to develop their abilities, (2) influence attitudes in the family and (3) make necessary changes in the physical environment.

CBR was seen as a type of rehabilitation with the following advantages:

– Quality: Rehabilitation within ones' own community makes it easier to participate in family and community life.
– Coverage: Institutions, if existing at all, can only provide rehabilitation for a limited number of people with disabilities and/or certain types of disabled people. Through CBR it is possible to reach all people with disabilities.
– CBR not only enables people with disabilities to develop their abilities but also influences attitudes and the physical environment.
– CBR is far more cost-effective than IBR.

The evaluation report criticised IBR services because of its inaccessibility, costs, and reliance on foreign resources (including expatriate manpower), but also stipulated the importance of the existence of a referral system and resource centres (rehabilitation institution, medical college) to train, supervise, monitor, and evaluate the programme (WHO, 1982 page 9). This indicates no real opposition to institutions but demonstrates a difference in expectations of what type of assistance institutions should offer.

As its target the WHO stated that by 1989 *"at least 50% of all countries will have initiated community-based rehabilitation programmes that are available and acceptable to all sectors of the population, especially the rural and urban poor, concentrating on the major categories of disabilities or handicaps caused by locomotor, speech, hearing, seeing and mental disorders"* (WHO, 1982). It is notable that the central criterion in this target is the number, and accessibility, of CBR projects, and not, for example, the number (or proportion) of people with disabilities benefiting from rehabilitation services. Thus, this target focuses not on the overall aims of providing services (e.g. equalisation of opportunities or improvement of quality of life) but on the means to reach these aims. It illustrates clearly that the WHO had no doubt that CBR was not only an appropriate way of providing services but, in fact, it was the only way to do it. It also marked the perceived one-dimensional relation between the programme and benefits to people with disabilities.

On the basis of the problems, the interventions, and the outcomes outlined above, the WHO approach to CBR can be characterised as a straightforward, linear process. The model presented in figure 1.1 (page 6) represents this.

This presentation of the problems, interventions, and outcomes of CBR might help to understand the WHO-CBR concept, but it also induces a number of comments and questions on the items mentioned and the relation between problems and interventions. For example, in this model the problems are defined as personal disadvantages of people with disabilities in a direct relation with the limited resources of the society to solve these problems. The underlying belief in this approach is apparently that there are so many people in need of help but there are even more people willing to help if they had the knowledge and skills to do so. In fact, in this model 'ignorance' is assumed to be the main problem in helping people with disabilities.

Problems

1. 7-10% of the world's population is disabled.
2. Being disabled causes serious social, economic, physical and psychological problems (low socio-economic status, victimisation, social isolation).
3. No more than 2% of people in need of some kind of rehabilitation are getting adequate help.
4. Institutionally based rehabilitation (IBR) cannot meet the demands.

Interventions

5 Client:
- Training of activities: develop abilities.

6 Family:
- Training of family members.
- Influencing attitudes in the family.

7 Community:
- Promoting awareness, self reliance, and responsibility for rehabilitation.
- Mobilising manpower resources in the community and using existing local structures (e.g. training volunteers, school teachers).
- Make changes in physical environment.

Outcomes

8 The CBR approach is appropriate, effective, feasible and economically viable:
- Through CBR all people with disabilities have access to rehabilitation.
- CBR enables people with disablements to develop abilities.
- CBR enables people with disabilities to participate in family and community life (equalization of opportunities).
- Through CBR attitudes and physical environment is influenced.
- CBR is cost-effective (compared with IBR).

9 The WHO manual is a valuable, practical tool: training results are equal to those of IBR.

Figure 1.1 Problems, interventions and outcomes as discussed in the WHO-CBR concept

Offering education and training is then assumed to be (part of) the solution to the problem. Whereas this might be a valuable working process, it requires a theoretical basis on, for example, how to actively involve other people in the process and how to make their interventions effective.
With all the uncertainties noted, it should be realised that the 'advantages' mentioned by Mendis & Nelson (1983) are in fact 'claims' that were based on ideas, assumptions and the results of the field-testing as presented by the WHO. These claims definitely expressed great faith and optimism in the possibilities to change attitudes towards people with disabilities, to mobilise communities, to formulate common objectives, to share economic resources and to refrain from individual gain. However, at this stage no substantial research to support these 'advantages' or 'claims' had been carried out and published.

1.2 The descent of CBR

With CBR, a formal system of rehabilitation has been introduced to developing countries as an alternative to, or alongside, rehabilitation offered in institutions. Institutions were absent or considered inadequate to meet the needs of people with disabilities. Increasing the capacity of institutions was not a viable option because of the costs, the lack of professional rehabilitation workers and other personnel, and for ideological reasons. However, the shortage of formal rehabilitation services that was observed does not imply that rehabilitation was non-existent or no support was given to people with disabilities. In any community, and at all times, people with disabilities have lived their lives and have (re)habilitated themselves in the absence of formal trained rehabilitation workers and with or without the help of family and community members. Miles collected historical examples from African and Asian practices and illustrated how people with disabilities have been able to fulfil meaningful roles in their family and community (2000). It can also be noted that special places and separate communities for people with disabilities existed long before Western missionaries and physicians started building institutions and provided a formal type of rehabilitation. These special places were meant to prevent contagion (e.g. leprosy) or to form communities where people with disabilities could live in a sheltered - or adapted to their needs - environment (e.g. people with visual problems or hearing problems). More recently, communities or self-help groups of disabled people like "Project Projimo" have been established (Werner, 1990). In developing countries, institutions for people with disabilities are a relatively recent phenomenon, mainly set up in the last century. Although early initiatives are known, for example in Zambia and Malawi schools for the blind started in the early years of the 20th century (Miles, 2001), most institutions were only set up in the second half of the century. In Zimbabwe, a "school for the deaf" started in 1947, the Jairos Jiri association (Children's centres and sheltered workshops) began its activities in 1951, and only from 1954, several medical and vocational rehabilitation centres were established (NASCOH, 1986).
To understand the development of CBR and the support it got, it needs to be related to developments in Europe and North America and the introduction of Primary Health Care (PHC). Up to 1970s, it was common to train and take care of people with disabilities (i.e. people

with severe learning problems, mental disorders, or severe physical limitations) in institutions and to accommodate them for a certain period or even permanently. In the early seventies de-institutionalisation, normalisation, and mainstreaming became leading concepts in the care of people with disabilities (Wolfensberger, 1985, 1980). It was argued that people with disabilities should live their lives with, and like, all the other people, and that society has to adjust itself to people with physical limitations or to those who behave or look different. In the same time period the PHC approach was developed and promoted as the best way to improve health in developing countries (Walt & Vaughan, 1981). Essentially, PHC aims to make essential health care accessible to everybody. Both concepts, PHC and de-institutionalisation, stressed community involvement and included a change in the locus of control and the use of resources accessible to the community. This way of thinking appears to be most relevant in the discussion on CBR and must have geared the development of CBR. CBR is presented as part of PHC and the PHC approach is *"therefore ...the general approach of WHO for preventing disability and providing rehabilitation"* and the two principal strategies are prevention of disability and provision of essential rehabilitation care (WHO, 1981).

Undoubtedly, the limited resources available for rehabilitation of people with disabilities in developing countries, combined with the assumed high number of people in need of help, have been of decisive importance in promoting CBR as the dominant model for rehabilitation in developing countries. However, the model could only be developed because of the paradigm shift in organising support for people with disabilities in Europe and North America and the introduction of Primary Health Care.

With such a short history on, and experience with, institutional care of people with disabilities and, at the same time, an apparent tradition of people with disabilities living in their own community, it is not easy to understand why and how Community-based rehabilitation models are introduced in developing countries. There is no documented opposition to rehabilitation in institutions by rehabilitation workers or by people with disabilities. In general, rehabilitation does not appear to be a priority on the political agendas of the governments of developing countries. There are a few examples where governments, in the early years of CBR, made 'disability' a political issue and incorporated it in Health Care, Social Welfare, or Labour programmes. In Zimbabwe, an effort was made to rehabilitate disabled war veterans after the war ended in 1980. Rehabilitation units, orthopaedic centres, and vocational training centres offered medical rehabilitation, appliances, and vocational training for these people. However, in general, developing countries will concentrate on providing the basic needs for the people, and this does not appear to include rehabilitation services for people with disabilities. Even the loss of part of the working force due to disabling conditions is apparently not a political issue, probably because of the overall high unemployment rates in developing countries.

1.3 Defining Community-based rehabilitation

The original definition of CBR by the WHO (1981) has been presented above. In the evaluation report (WHO, 1982) it was mentioned that in 1981, UNICEF and WHO signed a joint statement on co-operation in supporting CBR and in 1982 a similar statement was made by

UNDP, UNICEF, WHO, UNESCO, and ILO. Their emblems all appear on the cover of the CBR manual (Helander et al., 1983). This at least suggested that the UN organisations agreed upon the use of the term CBR to define a mutual approach of developing support for people with disabilities in developing countries. However, it is remarkable that not all of these UN organisations adopted the term CBR in that period. UNICEF, for example, used in its publication "The Disabled Child, The family and the Community" (UNICEF, 1982) terminology like 'community participation', 'empowerment of communities' and 'community support' but never resorted to CBR or Community-based rehabilitation. In the "Vienna Affirmative Action Plan" (United-Nations, 1982), the key slogan is 'Equalization of Opportunities'. CBR was mentioned here as an important innovative approach, and WHO's definition on CBR was given. However it is added that specialised institutions are *"useful for resource and referral purposes"*. In the "Manual on the Equalization of Opportunities for Disabled Persons" (United-Nations, 1986), the term CBR was not used anymore. The authors objected to the creation of an 'either/or' dichotomy of developing highly specialised services in urban areas, or completely decentralized 'community-based services'.

Momm & König (1989) stated that *"the CBR approach is part of a movement which received global recognition with the adoption of the World Programme of Action for Disabled Person"*. The document "World programme of action concerning disabled persons" (United-Nations, 1983) offered a comprehensive view on disability and rehabilitation and stressed the involvement of the person with a disability, the family, community, and local authorities in the rehabilitation process. All the basic elements of CBR were present, but the term CBR was never used. Even when referring to the work of the WHO, it was mentioned that the WHO would apply the concept of PHC to health aspects of disability.

Having observed that the term CBR did not get support of the other United Nations organisations, it is worth noting that the ILO published a report on the Indonesian Rehabilitation Programme with the title "Community-based rehabilitation services for the disabled" (ILO, 1982/1985). This report mentioned that *"In order to step up rehabilitation efforts, particularly in rural areas, the Government of Indonesia (Department of Social Affairs) recently embarked on an innovative programme of non-institutional community-based rehabilitation services for the disabled. The ILO and UNDP have been collaborating in the development of this new programme since 1979"*. A few years later Momm & König, working for the ILO, commented ironically: *"Rarely in the history of services for disabled people has an idea attracted so much unqualified support as has 'community-based rehabilitation' (CBR)"* (1989). It is probably significant that in a later edition of the manual (Helander, Mendis, Nelson, & Goerdt, 1989) the ILO emblem does not appear on the cover anymore. It would take up to 1994 before the UN organisations ILO, UNESCO and WHO, managed to publish a 'joint position paper' on CBR (ILO, UNESCO, & WHO, 1994).

The perceived dichotomy between community and institutionally based services has greatly influenced the discussion on CBR. In the 1989 edition of the manual (Helander et al., 1989), three approaches to rehabilitation were outlined; institution-based rehabilitation, outreach services for rehabilitation, and Community-based rehabilitation. It was added that CBR *"also includes referral services at district, provincial, and national levels"*. As such, institution-based rehabilitation services are seen as a back-up service for CBR i.e. for people with disabilities with

complicated problems and for training of personnel. However, this pragmatic and conciliating approach cannot disguise the different approaches to the needs of people with disabilities by, for example, social workers, physiotherapists, or human rights activists. Wolffers & Finkenflügel (1993) described the confusion about the 'real interpretation' of CBR as the result of a conflict of interests. It should be recognised that people involved in rehabilitation have different priorities and will use different terminology to bring forward their point of view and to distinguish themselves and 'their' CBR-programmes from others.
In 1994 three UN organisations (ILO, UNESCO, and WHO) published a 'joint position paper' and compromised on a new definition of CBR (ILO et al., 1994):

> *Community-based rehabilitation (CBR) is a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services (ILO et al., 1994).*

This new definition stressed that CBR is a *strategy* within community development. The former definition opened with *"CBR involves measures..."* and was formulated at an operational and tactical level. The new definition embedded CBR in community development without giving a direction to this development. Equalization of opportunities and social integration of people with disabilities became touchstones in the appreciation and evaluation of community development. The basic principle appeared to be that people with disabilities should take part in, and benefit from, community development. Whereas the former definition explicitly mentioned *"community level"* and *"resources of the community"* in the new definition this is rephrased as *"combined efforts of..."*. Although 'community' has not been defined in the former and new definition, the understanding of 'community' seems to be shifted. In the former definition, the community had been perceived as a relatively well-confined (geographical) entity. CBR was very much a model for rehabilitation of people with disabilities living in rural areas. The new definition allows CBR to be a pragmatic mix of rehabilitation in the community, through outreach or support services and in specialised centres. Community now seems to be used more in terms of groups of people who might live in proximity but can also be formed based on religion, descent, or a common interest.
The new definition very much reflects the way CBR projects have actually been carried out (often as a combination of different types of rehabilitation services) and tries to meet the criticism that CBR was presented as an exclusive and prescriptive programme. However, this consensus definition disguises what have been considered as key elements of CBR i.e. the involvement of lay people in the training of people with disabilities, the needs-driven approach, and the ownership of the programme.
The leading concepts in the new definition are *'rehabilitation'*, *'equalization of opportunities'*, and *'integration of all people with disabilities'*. Integration appears to be the aim of CBR, and rehabilitation and equalization of opportunities are the conditions to reach this aim. In terms of the ICF (WHO, 2000, 2001, 2002) the definition includes interventions at all three dimensions:

ICF		Definition
Body functions & Structure	-	Rehabilitation
Activity	-	Rehabilitation, Equalization of opportunities
Participation	-	Integration

It cannot be derived from the definition how the aim and conditions are related in the rehabilitation process and what type of interactions are required between the people involved. The second part of the definition talks about *'combined efforts'*, but this leaves the responsibilities of the people involved in the CBR programme open.
The discussion on CBR and its definition seems to have calmed down after the 1994 'joint position paper'. However, it might very well be that the discussion on CBR is still existing but hidden in a semantic discourse. People involved in rehabilitation appear to be reluctant to use the term CBR for their programmes and resort to a new name for the programme or approach; for example Community Disability Studies (Chalker & Wirz, 2002) or community based support for people with disability (S. Miles & Medi, 1994; Tembe, 2002).

1.4 Use of terminology

Many terms used in the field of rehabilitation have been reason for discussion and confusion. Terminology apparently changes to underline a change in the approach, to point at differences, to avoid (negative) connotations, to make it more acceptable or political correct, or to simply distinguish an approach from others. The use of 'CBR' has already been discussed above and other essential terms will be discussed briefly hereafter.

1.4.1 People with disabilities

In the literature, many words or phrases are in use for people with disabilities. In this thesis 'people with disabilities' has uniformly been used, even when authors used a different terminology. This has, of course, not been done in quotations. In accordance with the International Classification of Functioning, Disability and Health (WHO, 2001), 'disability' is being used here as an umbrella term for impairments, activity limitations, or participation restrictions.

1.4.2 Rehabilitation

In this thesis, 'rehabilitation' is used in a broad context and includes all type of interventions aiming to improve the functioning and participation of a person with a disability. This includes all types of support; e.g. counselling, (special) education, vocational training, and different types of medical rehabilitation.

1.4.3 Institutions, specialised centres, referral centres, resource centre

When discussing 'institutions' and 'institution based rehabilitation' in the context of CBR, reference is made to a building, a physical structure, of an organisation where people with disabilities can go for assessment and receive training and care from professional rehabilitation

workers and other staff. In the discussion of CBR, institutions are typically places where people with disabilities stay for a length of time or even for their whole lives. These can be rehabilitation centres, vocational training centres, schools for people with disabilities in combination with boarding facilities, residential homes for people with (severe) learning problems, and hospitals for people with mental disorders.
Institutions, specialised centres, and referral centres cannot easily be distinguished. In CBR, specialised centres and referral centres are seen as places where rehabilitation workers, doctors, or other specialists are available for advice on, and treatment of, people with complex disabilities who cannot be given adequate support in the community. In general, the aim of a referral is to continue training in the community at a later stage.
Resource centres were already mentioned in the evaluation report (WHO, 1982) and were responsible for training rehabilitation workers, treating people with complex disabilities, and monitoring and evaluating CBR projects. The term 'resource centre' is also being used for a centre where people with disabilities and their caregivers could meet to discuss the problems, experiences, and solutions found with each other, to find information and to get advice from rehabilitation workers. This type of resource centre can actually be 'community-based'.
In the discussion on CBR, 'institutions' have been negatively labelled but at the same time the need for specialised centres, referral centres, or resource centres has been stressed. However, the line between 'institutions' and 'centres' may be thin. Many institutions have outpatient clinics and outreach services, and they function as referral and resource centres for CBR projects.

1.4.4 Community

Community is probably the most amorphous term used in CBR. Helander (1993) stressed the diversity of communities and came up with the following definition:

> *"A community consists of people living together in some form of social organization and cohesion. Its members share in varying degrees, political, economic, social and cultural characteristics, as well as interests and aspirations, including health. Communities vary widely in size and socio-economic profile, ranging from clusters of isolated homesteads to more organized villages, towns and city districts".*

In CBR the community is assigned a central role in the rehabilitation process and therefore who belongs to that community and what the community's perception is on a person with a disability should at least be clarified. 'Community' is clearly not an unambiguous concept and many controversies arise when looking more closely at it.
In CBR, the impression is given that people with disabilities are part of one, identifiable, community. However, it probably makes more sense to accept that people belong to several communities if we consider the place to live, to work, to meet friends, or to spend free time. People live, work, and recreate with other people and often in different groups. People belong to some groups by birth or descent, but other groups are self-chosen. Some groups are more or less closed entities with strict rules that belong to the group whereas other groups are transparent and diffuse, and people will join and leave these groups depending on their actual

interest. Jewkes & Murcott (1996) noticed an interesting difference in definition of 'community' by 'non-members' or 'members': *"...whilst non-members may construct communities from whatever symbols of boundary they wish, when they attempt to operationalise their definitions difficulties may be encountered if the boundaries do not reflect the ´members´ own sense of similarity and difference"*.

It should also be noted that the word 'community' is sometimes used to describe a group of people with similar backgrounds or attributes and which form a cross-section of 'community' in terms of administration. This can be profession (e.g. the farmer's community), by religion (e.g. the Christian community), by descent or ethnicity (e.g. the Indian community), or even by presentation (e.g. the disabled community).

When rehabilitation workers use the word 'community', they seem to refer to a system that is willing and capable to care for a person with a disability. However, the concept 'community' has been used in many ways: community participation, community development, community care, Community-based rehabilitation, etc. Hospitals offer (decentralised) services in the community and label them as 'community-based' while actually the services are community-oriented or community-level (Helander, 1989). Often community-based is used similarly to a bottom-up approach to illustrate that the needs of the people in the community are the reason for the services, and that the higher levels of service are developed in response to community needs.

In this thesis, no attempt has been made to define 'community'. When it is necessary to specify 'community' to understand a project, process, or intervention it will be assessed in that specific situation or from the available documentation.

1.4.5 Stakeholder

The new definition of CBR states that *"CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services"* (ILO et al., 1994). To express that all these people have a say, or a 'stake', in the programme, they are referred to as 'stakeholders'. In line with the WHO-CBR model, six (groups of) stakeholders can be listed:

- At community level:
  1. The person with a disability.
  2. The family and family trainer.
  3. The Community Rehabilitation Worker (CRW) or Local Supervisor (LS).
- At district level:
  4. The Rehabilitation Assistant (RA), Rehabilitation Technician (RT) or Intermediate Level Supervisor (ILS).
- At provincial level and/or at referral facilities:
  5. The trainer.
- At national level, referral facilities, and training centres:
  6. The specialists.

1.4.6 Empowerment

According to the dictionary, 'empowerment' means *"to give lawful power or authority to act"*[1]. In development issues this originally legal meaning has been broadened to include topics like

'participation', 'ownership', 'capacity building', 'self reliance', and 'human rights'. In rehabilitation, 'empowerment' seems to be reserved for the people with disabilities and their families (e.g. Helander, 1993; Stewart & Bhagwanjee, 1999). This is what Wolffers (2000) called 'personal empowerment' which can be defined as making people aware of their skills and possibilities to improve their situation. In addition, he defined 'community empowerment' as strengthening the community as a whole to demand changes and call for a supportive environment and 'social empowerment' as claiming and exerting equal rights and recognition of special needs without being made exceptional or being stigmatised.
In this thesis, 'empowerment' is, in all three dimensions, used as a central element, and aim, for all stakeholders. The rationale for this is that CBR is seen as a process in which different stakeholders are empowered to exert their competency and to influence their position in the process. It could be argued that empowerment of community workers and rehabilitation workers is a means for empowering people with disabilities and not an end in itself. However, this relies too much on a perceived altruistic attitude of these stakeholders and tends to devalue their own interests. If CBR is to be seen as a 'democratisation' of rehabilitation services, the interests of the different stakeholders should be treated equally.

1.4.7 CBR programme and CBR projects

CBR has been described as a scheme, strategy, concept, approach, and programme. These terms have been used to address different levels in the programme but apparently even exchangeable. Although no real objection can be made to any of these terms, in this thesis, preference is given to use of the terms 'CBR programme' in combination with 'CBR projects'. 'CBR programme' then refers to a defined implementation process with objectives to be achieved, and it is based on a theoretical background of CBR in combination with the availability of a monitoring and evaluation system. The term 'CBR project' is then reserved for CBR in practice and is generally derived from a CBR programme.

1.5 Challenging CBR

The conclusions of the WHO evaluation (WHO, 1982) have been challenged by professionals in the field of rehabilitation (e.g. programme implementers, rehabilitation workers, evaluators, anthropologists). In the past twenty years they have been engaged in a lively debate on the concept of CBR, implementation strategies, and the effectiveness of CBR programmes. In the 1990s people with disabilities themselves got increasingly involved in the debate. There appeared to be a consensus that people with disabilities did not get adequate support and that they, as well as their families, were highly at risk for impoverishment. CBR was promoted as an affordable and appropriate approach to address the needs of people with disabilities, but the relevance and effectiveness of the CBR approach has, however, been continuously queried, and the discussion has not yet ended. Some researchers and people involved in CBR projects go as far as saying that if CBR cannot provide better evidence of being an effective programme, policymakers and funding agencies might no longer be interested and CBR will fade out (Wirz & Thomas, 2002).

The documented support of CBR consists of a wide range of sources, e.g. project reports, individual accounts of people with disabilities involved in CBR, conference proceedings, theoretical reflections on the concept of CBR, and evaluation studies of CBR projects. Most of the documentation allows a glimpse on a specific CBR project but does not contribute to the 'evidence' of CBR. Evaluation studies are generally concerned with the outcome of the rehabilitation process, e.g. functional progress of people with disabilities, the number of the people assisted by CBR, or the costs of rehabilitation per client. Due to methodological problems in the studies and the broad spectrum of CBR projects studied, generalisation of results and drawing conclusions that go beyond the particular project is hardly possible. In addition, the information generated through outcome studies does not provide insight into the rehabilitation process itself as the process itself is not well defined and the interventions and expected changes are not accounted for based on a theory. Looking at the process in CBR, the most striking characteristic is the training of a person with a disability by lay people instead of receiving therapy or training by professional rehabilitation workers, educators, or vocational trainers. Having noted this, it is remarkable that the involvement of lay people and the process of transferring skills and responsibilities got so little attention from researchers.

1.6 Research questions

This thesis aims to provide insight into the rehabilitation process in CBR and, by doing so, contribute to the body of theory about CBR. The assumption is that a clear understanding of the process will make it possible to set up interventions in a more effective and accountable manner and will guide the development of CBR. The central question in this research study is:

> *What, so far, is the knowledge and evidence base for CBR, and to what extent can an analysis of the roles, interests, and powers of the different stakeholders involved add to the body of knowledge and further development of CBR?*

The concept of stakeholders is seen as crucial in revealing and assessing the process of CBR. The idea to be discussed here is that CBR can only succeed and be sustained if people with disabilities, family members, community members, planners, policy makers, and other people involved in the rehabilitation process are confident and competent to fulfil the assigned roles. This includes processes such as defining goals, making decisions, using information, and working together. The study presented here is an explorative study, and is based on a study of literature on CBR, case studies and field experiences. Any comprehensive essay on the concept of CBR would include countries from different parts of the world with different cultures, states of development, economic resources, and political and religious structures. This thesis concentrates mainly on research studies, project reports and articles from the ten countries in the Southern African region (Angola, Botswana, Lesotho, Malawi, Mozambique, South Africa, Swaziland, Zimbabwe, Zambia) with the purpose to limit these differences (see figure 1.2, page 16).

Figure 1.2 Map of Southern Africa

In order to be able to answer the central question, it is subdivided into four questions. These will be introduced and formulated hereafter.

1. CBR has been developed as a programme to offer services to people with disabilities in developing countries. The emphasis has been on the applicability of the programme. Initiating actions was more important than the development of a programme theory. This is not to say that CBR is necessarily a-theoretical. The starting documents (i.e. Helander et al., 1983; WHO, 1976) as well as all the publications that followed in the 20 years thereafter, together constitute a body of knowledge that can be used for theory building. It is not uncommon in social sciences that 'treatment practice' runs ahead of 'treatment theory' (Lipsey, 1993). However, existing evidence deriving from practices might threaten the construction of a consistent theory on CBR.

   Question 1:
   Can a programme theory for CBR be identified or constructed, and how can this theory function as a framework for designing interventions, evaluating the process, and strengthening the roles of the stakeholders involved.

2. With the introduction of CBR an alternative and complementary service to rehabilitation in institutions was created to support people with disabilities. Institutions have been portrayed as expensive and inaccessible places with mainly expatriate rehabilitation workers in which people with disabilities learn skills that they would not be able to use in their own, rural environment. The 'promises' of CBR were offered as an answer to this perceived failure of rehabilitation practices in institutions.

   Question 2:
   Do research studies provide evidence that CBR is a relevant and effective alternative for rehabilitation for people with disabilities in developing countries?

3. The assumed high number of people with disabilities, their perceived marginal and vulnerable position, and the lack of adequate and accessible rehabilitation services motivated the start of CBR. People with disabilities have been positioned as a group who cannot fully use their abilities and cannot maximise their position in the family, community, or society. The assumption was that rehabilitation would empower them and enable them to function better and (re) gain a role in the community. However, such a dichotomy ('people with abilities' vs. 'people with disabilities') might be too simple. A person's position in a community is most likely a combination of personal characteristics (e.g. age, sex, descent, physical abilities, intelligence), living circumstances (e.g. health status, access to land and water, mobility), and qualities attributed to her/him by others (e.g. wisdom, extra-natural powers). The CBR approach leaned heavily on the assumption that people with disabilities, families, communities, and local authorities share a common analysis of the problem that people with disabilities encountered, and that the people involved are willing and able to change this situation.

   Question 3:
   Which stakeholders are relevant in CBR, how do they play a role in the rehabilitation process, and how can they be empowered?

4. Evaluation studies generally do not focus on the specific roles of, and the interaction between, the stakeholders. Therefore, based on these studies, powerful or weak stakeholders, or interactions between stakeholders, cannot be identified, and effects within the project cannot be attributed to one or more groups of stakeholders.

   Question 4:
   How can knowledge about stakeholders steer the planning, implementation, monitoring, and evaluation of CBR projects?

1.7 Research methodology

CBR is a complex process with many people involved in a project in a natural, and thus more or less uncontrolled, environment. Outcomes of a project cannot easily be causally related to specific interventions and side effects cannot always be accounted for. Consequently, it will be difficult to maintain or improve these outcomes and to compare these to different circumstances or other projects.
The complexity of CBR poses challenges to carrying out and interpreting research. Research in CBR is mainly applied research following or joining up with the implementation of CBR projects. The emphasis is generally on effectiveness of interventions, not on theory building. In CBR research, the input (e.g. training of volunteers) is manipulated by the researcher and a change in outcomes is observed, or the researcher observes variations in input and relates these to variations in outcomes. The underlying, connecting process is not readily visible. This 'black box' approach is unsatisfactory for at least three reasons. First, this type of research does not

give an insight in underlying mechanisms and causal relations and tends to simplify and reduce reality. Lipsey (1993) argued that in a minimal form this type of research is almost a *"try this and see if it works"* approach. Second, in intervention research, the independent variable is often a complex construct by itself, e.g. 'training of volunteers', 'instruction by community rehabilitation workers', and cannot be strictly defined. For example, training would include contents, duration, intensity, etc., and all these should be considered in establishing a causal relationship with the results found. The third reason is that interventions will be based on implicit understandings of the situation and covert ideas on the change mechanisms through which effects should be produced.

An alternative to a 'black box' approach is to start explicitly with a conceptual or theoretical framework that enables a differentiation between input, causal processes, and output, and one that illuminates the relations between these. Research will then focus on establishing directions and strengths of these relations. In addition, it analysis the influence of changing a variable (e.g. provide training) on other variables and its contribution to the prospected, or even unexpected, outcomes. This approach is known as a 'theory oriented' (Keith & Lipsey, 1993; Lipsey, 1993) or a 'theory driven' (Chen, 1990) approach. This 'theory oriented' approach is used in this thesis to understand and influence the relationships between the problems identified, the interventions, and the outcomes in CBR.

1.8 The structure of the thesis

The first part of the thesis is descriptive and based on the available documentation on CBR. A systematic review of the literature on CBR is presented in chapter 2, and in chapter 3 the development of CBR is discussed. CBR appears to be in a state where little progress has been made. In recent literature there is a demand for improving and standardising research methodology in CBR. Although this is considered important, it is argued here that first the process of CBR needs to be uncovered before research on the outcome of CBR will be meaningful. In this thesis the focus is on establishing the 'state of the art' and identifying key aspects in the CBR process, i.e. concerning the interventions by, and the relations between, the stakeholders. This will be taken as the conceptualisation or 'body of theory' of CBR.

The second part of the thesis deals with the roles, positions, and influences of the different stakeholders in the CBR process. Chapter 4 examines the perceptions on, and descriptions of, the different stakeholders and their perceived roles in CBR. Based on a description of the role and competence of stakeholders, a normative framework for the different stakeholders involved in CBR will be developed. In chapter 5 the roles of stakeholders in CBR projects in the Southern African region are analysed.

The third part of the thesis presents examples of empirical research on how different stakeholders in the CBR process perceive and use their position in the process. In the conceptualisation of CBR as well as in the normative description of the stakeholders, the use of a referral system and the appraisal of the expertise held by other stakeholders play an important role in the CBR process. In chapter 6 the referrals made to, and the actual use of, referral services in addition to the follow-up of home-based training programmes by

rehabilitation workers are examined in the CBR pilot projects in Zimbabwe (Ministry of Health, 1990). The caregivers of children with disabilities are the objects of research in chapter 7. The study described here was carried out in Zimbabwe, and it specifically explored the appreciation of CBR by caregivers of children with a disability.
The final part of this thesis, chapter 8, recapitulates the main research question and the four sub-questions. Four scenario's for the further development of CBR, as well as recommendations for a new research agenda, are presented.

Notes:
[1] Oxford Advanced Learners Dictionary 1989

2 The evidence base for CBR: a literature review

Abstract

In this chapter, literature on Community-based rehabilitation (CBR) published between 1978 and 2002 is reviewed. There were 128 found that met the criteria set by the author. The articles have been classified according to the methodology used, the key aspects studied, and the country or region to which the study refers. The review showed a still increasing number of publications on CBR, with an average of eight articles per year produced in the last five years. The majority of the studies concern CBR in the Sub-Saharan African region, followed by the next largest number of studies coming from the South Asia and East Asia regions. Only a few articles on CBR in South American countries could be found.

Theory papers and descriptive studies are the most common types of papers in CBR literature. Intervention studies and case reports are relatively rare. No systematic review has yet been carried out although reviews on specific aspects of CBR have become available. The key aspects 'implementation' and 'stakeholders' are relatively well presented but the numbers of articles on 'participation' and 'use of local resources' are noticeably low. Classification of the articles reveals that there is no real focus of research in CBR and therefore the evidence base for CBR is fragmented and incoherent on almost all aspects of CBR. It is recommended that specific aspects of CBR be researched in controlled settings. The findings can then be linked to specific characteristics of a CBR project and thus contribute to general knowledge on, and evidence for, CBR.

2.1 Introduction

Following its debut in 1976, the concept gained momentum after 1984 with many CBR programmes implemented in developing countries and, at the same time, an intense discourse on the concept by people working in, or studying, CBR. In the 1990s a period of consensus marked by the 'joint position paper' of the UN organisations (ILO, UNESCO, & WHO, 1994) was entered. In 1991 Thorburn wrote, *"A major problem in the study and evaluation of CBR is that there is no forum for publication of information and experience, so it is very difficult to find relevant reports"*. Documentation on CBR (e.g. project proposals, evaluation reports, annual reports, brochures, books, articles) has gradually become available in the past ten to fifteen years. The database 'Source'[1] - probably the most comprehensive and specific database on CBR in developing countries - gives over 1000 references when searching for 'Community-based rehabilitation'. Nevertheless, at the turn of the century, researchers commented negatively on the number and quality of studies on CBR that had been published. Lagerkvist (1998) remarked, *"CBR is gaining increasing interest but very few studies have been published"*, and Mitchell (1999b) added, *"Little quality research on CBR has been placed in the mainstream of scientific literature"*. Or, in the phrasing of Thomas & Thomas (1999), *"In spite of the recognitions of the need for research in this field, community based rehabilitation has grown on experiential accounts rather than with scientific research in the last decade"*. By 2002 Wirz & Thomas (2002) concluded: *"CBR has not developed sufficient published literature about planning, implementation, and evaluation in the same way as other areas of service delivery such as primary health care, community development or income generation"* and just recently, Miles (2003a) pointed at *"the modest amount of CBR research in refereed journals"*. He then stated that *"CBR knowledge is still thin, scattered, mostly unsifted, unreliable, unrecorded or unpublished"*.

In taking these comments seriously, questions arise regarding how many and what type of studies have been actually published, and which aspects of CBR have been covered. Or, to broaden the subject, what is the knowledge and evidence base for CBR after 25 years of experience with the concept?

It is notable that after 25 years of CBR no systematic review is available although some reviews on selected aspects of CBR have been published. For example, Hartley (1998) reviewed the development of services for people with communication disabilities in developing countries. Although she included CBR studies in this review, it was not written in a strict CBR context. The same applies to a review carried out by Wirz & Lichtig (1998) on the prevalence of hearing impairment in developing countries. However, in contrast with Hartley, their conclusion was phrased within the context of CBR (e.g. they concluded that CBR reaches disabled children more effectively). Another example of a review is the study done by Wirz & Thomas (2002) on 'indicators'. Based on a selection of evaluation and published reports they came up with a list of indicators to determine effectiveness of CBR programmes. A review on 'current research on CBR' was compiled by Mitchell (1999b). He collected literature to reflect on what he described as *"fundamental principles of CBR"*.

None of these reviews pretended to be comprehensive or complete. Miles (2003) commented that *"no serious, critical appraisal has yet been made of even a quarter of this material"*. Looking at the variety of documentation, the purposes for which it was written and, not the least, the availability of it, an appraisal of even a quarter of the material would already be an immense task. A task which is even more complicated when it is realised that CBR is not a concept that can be easily confined, but overlaps and takes bits and pieces from other concepts (e.g. community development, inclusion, empowerment, home care) and different scientific disciplines (i.e. medicine and social sciences). A study of, for example, the 'coverage of CBR' would involve literature on screenings, assessments, community based research, training of volunteers, needs-generated approaches, end-users of research, etc., and itwould therefore expand dramatically.

Notwithstanding the dissatisfaction of the quoted authors with the number of research studies, articles on CBR have been published in (peer reviewed) journals. In this chapter a pioneering effort has been made to present a review of these articles.

2.2 Objectives

The objective of this study is to ascertain to what extent the existing literature on CBR in developing countries provides an evidence base for CBR. The objective will be addressed by answering to following questions:

1. What is the number of studies on CBR published in (inter)national, peer reviewed, journals, and which developing countries or regions are leading, or absent, in publications on CBR?
2. What types of studies have been published, and which key aspects of CBR have been covered?

Based on the answers to these questions, potentially successful types and areas of research will be identified.

2.3 Methods

In the search, electronic databases (PubMed[2], PsycINFO[3], Source[1], CIRRIE[4], Rehabdata[5]) have been used. This search included, in different combinations, the key words: 'CBR', 'disability', 'rehabilitation', and 'community'. The search was extended with the use of (electronic) bibliographies[6, 7] and by scrutinizing articles on relevant references. Additionally the electronic databases were searched again using the names of (leading) authors (Helander, Miles, O'Toole, Thorburn etc.). Also, authors and organisations have been contacted directly to enable them to supplement the search results. The articles were obtained through library services[8], Internet (including E-journals), and by contacting authors directly. The search was done between November 2002 and March 2003.
The search revealed over 1000 references. Book chapters, newsletters, personal communications, unpublished reports, and conference proceedings accounted for half of it and were omitted. The reviewer screened the abstracts of approximately 500 references. These were all articles published in (inter)national journals. Articles were studied in full text when abstracts were not available, or when the information in the abstracts was incomplete or unsatisfying.

2.3.1 Inclusion criteria

In this systematic review a number of choices have been made in searching and selecting articles and in compiling the list of articles to be included. These are briefly described hereafter.

Community-based rehabilitation

Right from the start, the CBR concept was applied very differently. Even different titles were being used to mark 'own' and unique approaches and to move away from connotations attached to, and specific objectives and structure of, CBR. For example, Momm & König (1989) labelled their approach as 'community integration' and Miles (1989) introduced the term 'information based rehabilitation'. As they refer to CBR, these studies are part of the discourse on CBR and can be counted to the heritage of CBR. Other authors have systematically avoided using the term 'CBR' in their studies. For example, Frye (1992, 1993) used 'community based integration of rehabilitation', and S. Miles & Medi (1994) used CBS for 'Community Based Support' to stress social integration rather than medical interventions. Apparently, they place themselves outside the domain and the discussion of CBR. Since the objective of this systematic review was explicitly to establish the evidence base for CBR, only articles with 'Community-based rehabilitation' or 'CBR' in the title, key words, abstract, introduction, or discussion have been included.

Developing countries

CBR was initially developed as an approach to provide services to people with disabilities in developing countries. The concept has now increasingly been adopted by, and implemented in, developed countries. In this study, studies relating to CBR in developed countries are not included. The main reason for this is that in developed countries CBR is primarily described as an auxiliary service to existing hospitals, rehabilitation centres, institutions, etc. The challenge

of CBR was to provide services to people who had no access to services or knowledge about rehabilitation. This study limits itself to the original commitment of CBR and thus only includes CBR in developing countries. Developing countries are defined according to criteria set by the World Bank (undated) and countries in the so-called lower and middle-income range are included in this review.

Time period
The time period from 1976 to 2002 has been chosen for this study.

Language
Only articles in English will be included.

Journals
The criterion used to ensure the quality of the articles was that they were either indexed by the Index Medicus (IM)[9] or the Social Sciences Citation Index (SCI)[10], or they were listed in PubMed[2]. Editorials, letters to the editors, and descriptions of more private experiences were excluded. Articles in non-indexed or non-listed journals (e.g. World health, CHASA, Asia Pacific Disability Rehabilitation Journal, Disability Dialogue, Blind Welfare, and most of the national profession specific journals) have not been included. Chapters in (edited) books, conference proceedings, newsletters, annual reports, etc. were also excluded.

2.3.2 Classification of articles

The articles were classified by the year of publication, country or region, type of article and key elements of CBR. The types of classifications will be elucidated here briefly.

Year of publication
The review covers twenty-five years of CBR. This period was divided into five five-years periods. Each period was described according to its characteristics. This was, of course, arbitrary and the periods were not exclusive and tended to overlap. The first period 1978-1982 was seen as the early beginning of the CBR program followed by a rapid expansion in the second (1983-1987) period. The third period (1988-1992) was pooled with spirited critiques on the program. Consensus was sought in the fourth (1993-1997) period, and in the fifth (1998-2002) period the attention shifted to the scientific basis of CBR.

Country or region
The articles have been grouped into six regions according to a classification used by the World Bank (undated): (a) East Asia and Pacific, (b) Europe and Central Asia, (c) Latin America and the Caribbean, (d) Middle East and North Africa, (e) South Asia, and (f) Sub-Saharan Africa

Type of article
A classification of 'type of article' is made based on the methodology used in the article. Five different types of articles have been distinguished. The classification presented in table 2.1 is based on Helewa & Walker (2000).

Key elements

In his review Mitchell (1999b) followed the research priorities set earlier by the WHO (1988). These were 'service delivery', 'technology transfer', 'community involvement', and 'organisation and management'. He added 'epidemiology of disability' to it. In his review, 'service delivery' was not discussed separately, but he did examine 'target populations', 'disabilities', and 'locations'. Based on his review and the overview of the development of CBR, a different grouping of key aspects was made. This is presented in table 2.2.

Table 2.1 Classification of 'type of articles'

Type of article	Description
Intervention studies	Articles reporting on studies assessing the effect of an intervention for a specific group (e.g. a training programme has been implemented), studies comparing outcomes of interest of different groups of which at least one group has been subject to a specific intervention, and single case (n=1) studies. To be included, articles should enclose a description of the research design, the intervention, the research methods, and the results.
Descriptive studies	Articles describing outcomes of interest (e.g. income, ability to walk, educational needs, use of services) of a selected population at a defined moment (without an intervention being carried out) are included here. It includes Screenings as well as papers that report on the testing of instruments.
Case reports	Articles describing a particular CBR project, an approach to a specific problem or aspects of a CBR project.
Review papers	Articles based on earlier published work, which give an overview of knowledge in a specific area.
Theory papers	Articles that aim to provide a theoretical base for CBR ('grounded theory'). It includes ethnographic and phenomenological work as well as discussion papers and articles presenting general information on CBR.

Table 2.2 Key aspects of CBR

Heading	Subjects included
Screening	Disability surveys, prevalence studies, screening instruments, assessments, etc.
Knowledge	Knowledge, awareness, attitudes, behaviour, traditional beliefs, traditional healers.
Local resources	Use of local resources (funding, technology), cost effectiveness.
Participation	Integration, inclusion, participation, mainstreaming, accessibility.
Implementation	Development of services, implementation of projects, working with other organisations, ownership, disability rights.
Stakeholders	Stakeholders, community involvement, manpower planning, training.
Evaluation	Follow up studies, project evaluation, comparing different types of rehabilitation.

2.4 Results and analyses

The data obtained were analysed using SPSS (2000). It should be noted that this systematic review only includes studies on CBR, and more literature is available on rehabilitation in developing countries or on the different key aspects. For example, only surveys to identify people with disabilities, conducted in the field of CBR or under the label of CBR, are included here. This review thus 'ignores' studies carried out under different headings and extensive databases not specifically constructed for CBR.

2.4.1 Number of studies on CBR

There were 128 articles found that met the criteria set above. All articles are presented in the Appendix. The articles have been divided into five-year periods. The number of publications per period are presented in figure 2.1.

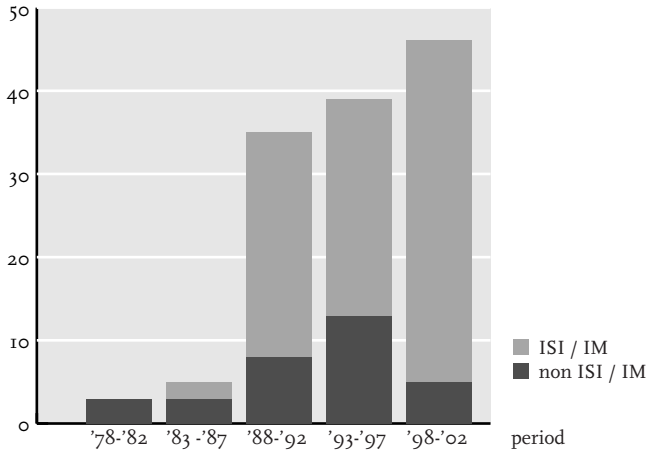


Figure 2.1 Number of publications per period

This figure illustrates that the number of publications - despite the pessimism expressed by Wirz & Thomas (2002) - is still increasing. Over the last five years, an average of eight articles per year on CBR have been published. Not only have more articles been published, but these have also been increasingly published in indexed journals. In total, 96 articles (or 75%) are published in 25 different indexed journals. Of these journals, 'Disability and Rehabilitation'[11] and 'International Journal of Rehabilitation Research' are well presented with 35 and 21 articles, respectively. These two journals account for almost half of all publications on CBR.

It was possible to specifically connect 100 articles to a little over 35 different developing countries[12]. Some studies described projects in different countries and in some cases even in different regions (Boyce, Johnston, Thomas, et al., 1997; Lagerkvist, 1992). Sub-Saharan Africa, South Asia, and East Asia and Pacific are best presented in 34, 27 and 22 articles, respectively. Figure 2.2 (page 29) shows the distribution of articles on CBR in the different regions.

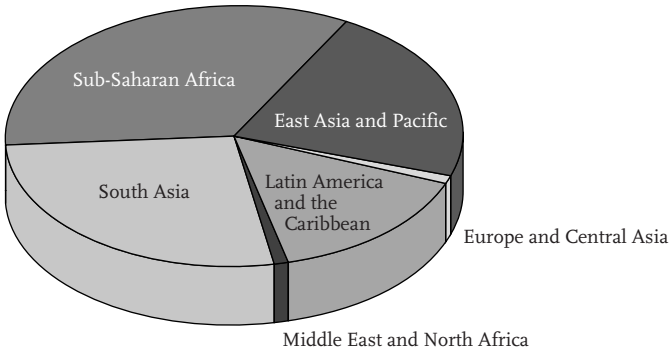


Figure 2.2 Distribution of articles per region N=102 (100 articles, two articles were counted in two regions)

Countries can be distinguished within these regions that account for substantial parts of the number of articles produced. Jamaica and India are listed in twelve and ten articles, respectively, followed by three countries in the Sub Saharan African region: South Africa, Botswana, and Zimbabwe (with nine, nine, and eight articles).

2.4.2 Types of articles published and key aspects covered

Types of articles

All articles have been classified according to the classification presented in tables 2.1. In some articles different types of studies were combined. For example, an intervention study that is introduced by a review or a screening followed by a more theoretical deliberation on the subject. In these situations only, the list has been used as a ranking list. As such, an intervention study preceded by a review was categorised as an intervention study. This choice is made to emphasize the original sources in CBR.

Some of the classifications remain debatable and might not accord with the opinion of the authors of the articles. Rao, Venkatesan, & Vepuri (1993) presented their work as an experimental study,but has been classified here as a descriptive study. It should be kept in mind that the classification of articles does not include a judgement of the quality of the articles. One article could not be classified. This article about modular handgrips for people affected by leprosy (Shah & Shah, 2000) states in the abstract that there is a shift from Community-based rehabilitation to 'work site based services'. This article then explains how to use the technique of making these grips without discussing the statement or CBR. The relative shares of the different type of articles are presented in figure 2.3 and in table 2.3 (page 30).

'Theory papers' were the most common type of article and contribute to more than 40% of all the articles included in this review. 'Descriptive studies' accounted for 30% of the articles but the number increased and, in the last period, even exceeded the number of 'theory papers'. Even though the numbers are still small, 'case reports' and 'review papers' increased considerably in the last period. Only a few intervention studies were carried out and even became almost non existent in the last period.

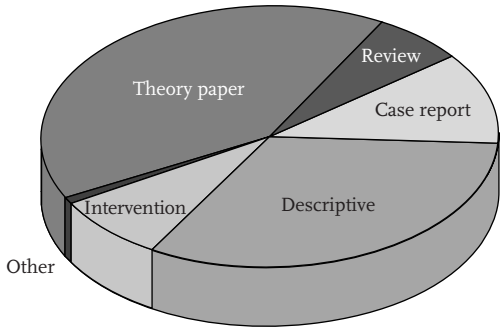


Figure 2.3 Types of articles published

Table 2.3 Types of articles published in the different periods

Types of articles	'78 - '82	'83 - '87	'88 - '92	'93 - '97	'98 - '02	**Total** n	%
Intervention studies	–	1	3	5	1	**10**	*8*
Descriptive studies	1	1	10	12	16	**40**	*31*
Case Reports	–	–	5	2	7	**14**	*11*
Review papers	–	–	2	–	6	**8**	*6*
Theory papers	2	3	15	20	15	**55**	*43*
Other	–	–	–	–	1	**1**	*1*
Total	**3**	**5**	**35**	**39**	**46**	**128**	*100*

Key aspects

Every article was classified by the aspects presented in table 2.2 (page 27). Only a single entry per article was allowed. In situations where two categories per article were applicable, the article was scored according to aims of the study. Evaluation, for example, was part of many studies. A study evaluating an instrument to screen children with disabilities could probably have been placed in both the categories 'evaluation' and 'screening'. Since the category 'screening' is considered more specific, it was then scored under 'screening'. An article on training volunteers to carry out a door-to-door screening would have been classified under 'screening' if the emphasis was on identifying people with disabilities more than on increasing the knowledge and skills of the volunteers. However, when the effectiveness of training auxiliary personnel was the main subject, the article was placed under 'stakeholders'. An illustrative example here is the study done by Pal, Das, & Sengupta (1998). Their survey to ascertain childhood epilepsy did not primarily aim at identifying children with epilepsy but at comparing the costs of two different survey methods. Therefore this study was classified under 'local resources'.

Table 2.4 Types of articles matched with key aspects of CBR

Types of articles	Screening	Knowledge	Local resources	Participation	Implementation	Stakeholders	Project evaluation	Other	**Total**	
	n	n	n	n	n	n	n	n	**n**	%
Intervention studies	–	1	1	–	–	3	5	–	**10**	*8*
Descriptive studies	13	6	1	1	5	7	7	–	**40**	*31*
Case Reports	–	–	–	–	8	5	–	–	**14**	*11*
Review papers	1	–	–	–	2	2	1	2	**8**	*6*
Theory papers	2	12	–	4	17	15	4	1	**55**	*43*
Other	–	–	–	–	–	–	–	1	**1**	*1*
Total	**16**	**19**	**2**	**5**	**32**	**33**	**17**	**4**	**128**	*100*
%	*13*	*15*	*2*	*4*	*25*	*26*	*13*	*3*		*100*

To gain insight into the aspects covered by the different types of articles, table 2.4 was constructed. This table illustrates that the different key aspects of CBR did not get the equal attention of the researchers. The key aspects 'implementation' and 'stakeholders' with thirty articles each were relatively well addressed. Remarkably, only six articles on 'participation', and two articles on 'local resources', could be found.
To find out if there was a changing interest or a 'fashion' in researching and discussing certain key aspects of CBR, the time periods and key aspects have been compared (table 2.5, page 32). It should be noted that with the number of publications increasing over time, all of the key aspects were better covered. However, 'screening' was the second best aspect covered in the time periods 1988-1992 and 1993-1997, but no articles on this aspect were published in the last time period.

The different types of articles will be discussed hereafter, and attention will be given to the key aspects of CBR covered in the research. At the end of this paragraph, some key aspects will be discussed complementarily.

Intervention studies
Ten articles were categorised as 'Intervention studies' or effect studies. The early study carried out by O'Toole (1988) can still be regarded as one of the most inclusive intervention studies. He used N=1 designs with treatment introduced at different times for each of the 53 children included in the study. The child was assessed using the Griffiths Test at different moments (before the project began, at the end of the fifteen month training programme, and six months

Table 2.5 Time period matched with key aspects of CBR

Period	Screening	Knowledge	Local resources	Participation	Implementation	Stakeholders	Project evaluation	Other	**Total**	
	n	n	n	n	n	n	n	n	**n**	%
1978 - 1982	3	2	–	–	–	–	3	–	**–**	–
1983 - 1987	5	4	–	1	–	–	1	–	**3**	–
1988 - 1992	35	27	9	4	–	–	9	10	**3**	–
1993 - 1997	39	30	7	5	1	4	5	12	**4**	*1*
1998 - 2002	46	36	–	9	1	1	14	12	**5**	*3*
Total	**128**	**100**	**16**	**19**	**2**	**5**	**32**	**33**	**27**	*4*

later), and the Portage test was used to evaluate improvement under controlled and treatment conditions. Questionnaires were used to measure the parent's perspective before and after the programme. O'Toole concluded that CBR is *"...one way of effectively reaching some of those who are presently unreached by any service"*. Rightfully he wrote *"one way"*, since this type of study, despite the demonstrated effectiveness, does not allow a comparison with other programmes. Control groups or alternative interventions were used in a few studies, but these do not include programme evaluations like the one O'Toole carried out. Powell, Mercer & Harte (2002) assessed the quality of life of people with disabilities who were receiving no services, single services, or a combination of services. A random selection of subjects within the research and control group was described by Mitchell, Zhou, Lu, & Watts (1993) in a study on attitudes towards people with disabilities, and in the study done by Finkenflügel, van Maanen, Schut, et al. (1996) on the appreciation of CBR by caregivers.

Only a few studies reported the use of a 'before-after' design, and of these most have established the 'before' situation retrospectively. Jagannathan, Ramamurthy, Jeyaraj, & Regina (1993) evaluated a community vocational training programme and mentioned that all subjects were either coolies or unemployed before the training. After training, seventeen out of the twenty subjects started earning money based on the skills learned. A slightly different approach was seen in the study done by Dolan, Concha, & Nyathi (1995). In assessing whether people with disabilities were satisfied with the input of Community Rehabilitation Workers they included questions on change that required the clients to look back and assess their situation retrospectively. This was also the case with Lagerkvist's evaluation of CBR projects in Zimbabwe and the Philippines (Lagerkvist, 1992). Clients and rehabilitation workers were, at the time of the evaluation, asked to assess and judge the functional level of the client at the start of the programme. A similar procedure was described by Mariga & McConkey (1987) in the evaluation of the Zimcare programme. External assessors evaluated the programme and

progress was established on the basis of interviews and observations held at the time of the evaluation. Finnstam, Grimby, Nelson, & Rashid (1989) evaluated the effect of training and did use a 'before-after' design. An initial screening, done by local supervisors and checked by a physician's examination, was followed by an assessment by an occupational therapist after one to two years of training. The same questionnaire was used, but the means of selection of the clients to be assessed after training (about one fifth of the original group) was not explained and therefore the results claimed by the authors should be interpreted with caution. The impact of CBR was also evaluated by Lundgren-Lindquist & Nordholm (1996). In 1993, they (re)assessed 77 clients out of 132 clients identified in a study carried out in 1990 (Lundgren-Lindquist & Nordholm, 1993). The studies compared ADL skills of the 77 clients in 1990 and 1993, but these data did not show any real differences. To assess the quality of life of the clients the authors resorted to a retrospective judgement by them *'How is your life today compared to three years ago?'*

It can be concluded that the use of a control group in combination with assessments before and after the intervention, or N=1 studies are not common in studying interventions in CBR. Almost all of the studies described are pre-experimental studies and should be interpreted with care. Caution should also be taken in generalising results. As far as can be judged from this review, the pre-experimental studies have not yet been used for hypothesis forming and controlled (quasi- or true-experimental) studies.

Looking at the methods used, it is apparent that the results of the intervention studies are almost completely based on questionnaires and interviews. Instruments like record studies, developmental tests, physical examinations, and standardised assessments of functional skills were not often used. Instruments developed by the IPSSCD/IESCD[13] group (i.e. the 'Ten Questions screen') were validated but apparently not yet used in intervention studies. One study (Werrij, Voeten, Adriaanse, & Thorburn, 2000) reported using OMAR (Jönsson, 1994), but this is the only experience with this instruments described and no studies on the validation of this instrument or the included questionnaires have been reported. More recently, researchers became involved in efforts to compile sets of indicators to be used to judge the effectiveness of CBR (Cornielje, Nicholls, & Velema, 2000, 2002; Wirz & Thomas, 2002). This work is still in a developmental stage, and no studies using these sets of indicators are available yet.

Descriptive studies

Problems were encountered in assessing and judging if the study was related to an intervention. In the above section on intervention studies, articles have been included that differentiated between people involved in CBR and people who were not (Finkenflügel et al., 1996; Mitchell et al., 1993; Powell et al., 2002). Although the intervention itself (the introduction of CBR) was not part of the study, it can be considered a manipulation of the situation. Therefore these studies have been classified here as intervention studies. On the other hand, studies were found on CBR aspects that lack a comparison with a control group or the situation before the implementation of CBR. For example, in her study Taukobong (1999) described the clients' perception of Community Rehabilitation Workers (CRWs). The introduction of this CBR cadre could possibly be approached as an intervention and it can be evaluated as such. However, these studies did not present a description of the intervention, nor

did they make use of a control group or baseline data. As these studies focus on a presentation of a situation at a given moment and thus do not attempt to establish change, they have been categorised here as descriptive studies. Finally, studies were found comparing a group with a certain, not to be manipulated, condition with a control group; e.g. Pal et al. (2002) surveyed the social integration of children with epilepsy and compared their findings with different control groups.

These judgements have resulted in 40 studies to be classified as descriptive studies. In general, these studies map different variables (outcomes of interest) of a population and aim at quantifying variables and exploring relations between variables. A typical example is the prevalence survey which is used to establish the number of people with disabilities, the type of disability, their needs, etc. The variables are not manipulated (like in intervention studies), but they might be stratified to be able to distinguish between groups (e.g. rural versus urban population) and to identify potential (causative) relations between variables. Articles reporting on validating and comparing instruments to be used in descriptive or intervention studies were also categorised under 'descriptive studies'.

Out of the 40 studies, eight can be classified as straightforward prevalence studies investigating the number of people with disabilities and their needs within the project area (Amstel, Dyke, & Crocker, 1993; Coetzee & Kemp, 1982; Finkenflügel, 1991b; Finnstam, Grimby, & Rashid, 1989; Grimby, Finnstam, Nelson, & Rashid, 1988; Katzenellenbogen, Joubert, Rendall, & Coetzee, 1995; Lundgren-Lindquist & Nordholm, 1993; Menon, 1984; Mitchell, Zhuo, & Watts, 1989; Palombi, Marazzi, Mancinelli, Sallabanda, & Buonomo, 1996; Pongprapai, Tayakkanonta, Chongsuvivatwong, & Underwood, 1996; Thorburn, Desai, & Paul, 1992). Menon (1984) presented a survey with limited and preliminary data on the outcomes of a CBR approach implemented in India.

There was no apparent consensus on the instruments used in the surveys. Self-developed questionnaires were used in house-to-house surveys. Classification was done by medical condition as well as by types of impairment and disability according to the ICIDH (WHO, 1980, 1997). Some research has been carried out to establish reliability and to validate the instruments used. Beach, Boyce, Peat, & Malakar (1995) reported on the inter-rater reliability of a self-developed instrument to assess the functional level of children with disabilities, and Thorburn, Desai & Davidson (1992) did so on the use of the ICIDH classification. Pal & Chaudhury (1998) used a factor analysis to test the internal validity of their test to measure parental adjustment and Thorburn et al. (1992) tested the internal validity of the Ten Questions screen (TQ) and the Ten Questions screen with probes (TQP). The validity of the TQ was also tested by Zaman, Khan, Islam, et al. (1990). In this study, they used a two-staged design in that the outcomes of the TQ were checked by professionals (medical doctors, psychologists, therapists). This design has also been used by Finkenflügel (1991b), Rao, Venkatesan & Vepuri (1993), and Mitchell, Zhuo & Watts (1989). Where these studies test the validity of the house-to-house survey, the survey itself has been used to test the usability and cost-effectiveness of 'key informants' to identify children with epilepsy (Pal, Chaudhury, Sengupta, & Das, 1998).

In descriptive studies the aim is not only to quantify 'outcomes of interest' but also to relate these outcomes to certain characteristics of the research population. Sorting the research group into subgroups can help depict differences. Common sorting strategies are age, gender,

different types of rehabilitation, and urban and rural populations. Evans, Zinkin, Harpman, & Chaudhury (2001) investigated the quality of medical rehabilitation in CBR and other rehabilitation services, and Lopez, Lewis & Boldy (1991) compared planned services and actual services. A differentiation between people living in urban versus rural areas was used by Khan, Ferdous, Munir, et al. (1998) when they investigated mortality of children with disabilities in urban and rural populations, and by Hosain & Chatterjee (1998) when they assessed the utilization of health care by disabled persons.
A wide range of more specific outcomes of interest have been researched. These include, for example, the parents' view on CBR (Thorburn, 1992), the follow-up of clients in CBR (Rottier, Broer, Vermeer, & Finkenflügel, 1993), neighbourhood support (Bischoff, Thorburn, & Reitmaier, 1996), and the repayment of loans (Gershon & Srinivasan, 1992).

Case reports

Fourteen case reports were found. Five articles described the implementation of CBR projects: four of these concern countries in Asia (Baolin & Huang, 1999; Hai & Chuong, 1999; Inthirat & Thonglith, 1999; Ran, Wen, Yonghe, & Honglu, 1992; Stuelz, 1999), and one article refers to Jamaica (Thorburn, 1991a). These articles had a more or less common structure: an overall picture of the country with a brief analysis of the perceived needs of people with disabilities, and the services available was given, followed by a description and discussion of the implementation process. Six articles (Finkenflügel, 1991a; Hartung, Kelly, & Okamoto, 1989; Maru & Cook, 1990; O'Toole & McConkey, 1998; Thibeault & Forget, 1997; Valdez & Mitchell, 1999) focused on the role of different stakeholders in CBR. One article (Boyce et al., 1997) illustrated four different examples of scaling-up CBR.

Review papers

In compiling this systematic review and classifying articles, it became important to distinguish between 'review' as an instrument commonly used in research studies, case studies, and theory papers and 'review' as a research method. Typically, 'review papers' aim to generate and generalise knowledge from different sources and do not present original research material (although the thoughts of the authors, and the way previous research has been approached, might be creative and original). Almost all of the 'intervention studies' discussed above include a review section. The research carried out elaborated on the findings of the review. Reviews were used to specify the research question as well as to answer part of it. Generally, issues like 'the magnitude of the problem', 'the shortcomings of existing service delivery systems', and 'the CBR concept' were discussed before presenting the studies' own research and results. 'Theory papers' often also included a review on the issue to be discussed, but the emphasis of these types of papers was on the development of a (theoretical) foundation for a given aspect of CBR. O'Toole's article on the 'problems and possibilities of CBR' (1987) was an example of combining a review on the development of CBR with a critical analysis of the methodology of the WHO evaluation of CBR. Another example was the recent study by Hartley & Wirz (2002). With the aim *"...to develop theories grounded in actualities..."*, the results of five earlier studies were rearranged to construct a 'communication disability model' which was subsequently compared with the WHO classification ICIDH-2 (WHO, 1997).

Eight articles were classified as 'review papers'. This included studies by Thorburn (1991b) and Nordholm & Lundgren-Lindquist (1999) summarising and discussing their own earlier work. The most generalised review was the one done by Chermak (1990). In this article, CBR was described as one of the international initiatives to address social integration of people with disabilities in developing and developed countries. The other review papers dealt with more specific issues. Hartley (1998) and Wirz & Lichtig (1998) reviewed literature on services for people with 'communication disorders' with the latter focussing on the use of non-specialists in identifying and assisting hearing impaired children. Mitchell (1999b) discussed the 'research base' of CBR (see also next paragraph). Wirz & Thomas (2002) reviewed evaluation studies on CBR with the aim to determine indicators to measure the effectiveness of CBR, and Turmusani, Vreede & Wirz (2002) looked for support of their argument that disability should be included in the development discourse. None of these reviews pretended to be comprehensive on the aspect covered, nor did they account for search results and the exclusion or inclusion of articles. The only exception here is the study of Wirz & Thomas (2002). They explicitly mentioned the criteria for inclusion evaluation reports but did not report on the initial number of reports available.

Theory papers

There were 55 Articles (43%) that were classified as theory papers. In these articles, the authors presented and discussed their view on (an aspect of) CBR with the aim to contribute to a theoretical foundation of CBR practice. These views were based on a certain, often personal, perception on the position of people with disabilities in the community, how society functions, and to what extent services meet the needs of people with disabilities and their caregivers. For theory building, related fields like psychology, sociology, anthropology, religious studies, etc. were explored, and selected elements were used to make recommendations to improve the practice of CBR.

Miles, the most productive author with eleven studies listed, first published on the topics of development of services, and he criticised institution-based as well as community-based approaches. He developed a more integrated approach and named it 'information-based rehabilitation'. Central in his work is the notion of 'existing realities' and the appreciation and sharing of knowledge and skills that already exists within the interaction between people with disabilities, families, communities, and professionals. In his more recent work he provided a historical analysis of the position and rehabilitation of people with disabilities (Miles, 1987, 1989, 1990a, 1990b, 1990d, 1993a, 1996, 1997, 1998, 2002a, 2002b).

It has mainly been anthropologists that have published on the implications of having a disability, the attitudes towards people with disabilities, and indigenous ways of handling and training people with disabilities. Devlieger (1989a), for example, presented an ethnographic study on disability in Zaire in which he systematically analysed the differences in perceptions of different types of disabilities. Unfortunately, only a few authors have combined ethnographic studies with a vision of how CBR can build on existing perceptions and knowledge. Kassah (1998) observed that people with disabilities preferred to migrate to town to beg instead of getting involved in CBR. Overcoming the stigma associated with a disability might just be too difficult for many people with disabilities and, consequently, they might prefer the (relative)

security of their role as a beggar. This role is apparently acceptable in urban Ghana society, and is probably the fastest way to gain some independence. Ingstad (1990, 1999a) and Whyte & Ingstad (1998) discussed what they called the *"myth of the hidden disabled"*. They argued that there is no evidence that families hide and mistreat their disabled children and that differences in handling and supporting children with disabilities might be due more to economic differences than to cultural differences. Families of children with disabilities are in need of support to help them to deal with the consequences of having a child with a disability, and perceptions on the disability might change if this support is effective in the eyes of people with disabilities and caregivers.

Studies on the implications of having a disability remain popular although the attention has shifted from more ethnological studies to consumer and human rights approaches. Again, linking consumer and human rights approaches to CBR is rare. In fact, only the study done by S. Miles (1996) dealt explicitly with this. She argued that CBR has the potential to play a key role in the development of DPOs (Disabled People Organisations) and to address poverty and lacunas in education, employment, etc. On the issue of 'participation of people with a disability in the community', Lysack (1997) discussed the concept of community, and Ferinho, Robb, Cornielje, & Rex (1993) described how a community development approach was used, but the issue has so far not attracted the amount of attention that could be expected since participation is proclaimed to be a key issue in CBR.

The majority of the 'theory papers' can be directly related to aspects of a CBR project. Thorburn (1993) and Thorburn, Paul, & Malcolm (1993) discussed methods to set up a screening of people with disabilities. The development of services and the implementation of projects was broadly covered in twelve articles (Cardenal, 1981; Gregory, 1996; Hai, 1993; Jelsma, Cortes-Meldrum, Moyo, & Powell, 1995; Johnston & Tjandrakusuma, 1982; Kibria, 1989; Marincek, 1988; Mitchell, 1999a; Momm & König, 1989; Peat, 1991a; Simeonsson, 1991; Stuelz, 1999; Thomas & Thomas, 1999), but only one article on evaluation of projects was available (O'Toole, 1987). Fifteen articles are concerned with different stakeholders in CBR. These are listed in table 2.6 (page 41) and briefly discussed in the paragraph on stakeholders.

A few authors have attempted to create order in the many different types of CBR that exist. Hartley & Wirz (2002) developed a communication disability model, and McColl & Paterson (1997), and Cornielje (2000) came up with a classification system for CBR. With the exception of the article by Thibeault & Forget (1997) who applied the model of McColl & Paterson to their case report no research is known using any of these classification systems.

2.4.3 Some supplementary comments on the key aspects covered

Screening

Sixteen articles report on surveys, screenings, assessments, etc. As discussed above, ten (descriptive) studies are prevalence studies establishing numbers and needs of people with disabilities. The other six are concerned with the methods (house-to-house Screening versus Key Informants) and instruments (Ten Questions Questionnaire) used (Thorburn, 1991b, 1993; Thorburn, Desai, & Davidson, 1992; Thorburn, Desai, Paul, et al., 1992; Thorburn et al., 1993; Zaman et al., 1990). All six studies branch from the earlier mentioned IESCD study.

Knowledge

The study of knowledge, attitudes, traditional beliefs, information, etc. makes up 19 articles and is thus predominantly within the domain of 'theory papers' and, to a lesser degree, 'descriptive studies'. The input of M. Miles with eight articles contributed to the dominance of theory papers in this key aspect (Miles, 1987, 1989, 1990b, 1990d, 1993a, 1996, 1997, 1998) His work focused on local knowledge of handling disability and disseminating appropriate information. Apart from his contribution only four studies discussed local beliefs and customs regarding people with disabilities (Ingstad, 1990, 1999a; Kassah, 1998; Whyte & Ingstad, 1998). Only one study was available on the effects of intervening on this aspect: Mitchell et al. (1993) studied the change of attitudes towards people with disabilities after introducing a CBR project. The five descriptive studies covered a wide variety of interests ranging from parental adjustment (Pal & Chaudhury, 1998), attitudes of Community Rehabilitation Workers towards people with disabilities (Paterson, Boyce, & Jamieson, 1999), traditional ways of handling children (Werrij, Voeten, Adriaanse, & Thorburn, 2000), the needs of families with children with mental retardation (Brodin & Molosiwa, 2000), and the training needs of relatives and Community Workers (McConkey & Mphole, 2000).

Local resources

The key aspect 'local resources' covers the use of local or appropriate technology and the cost-effectiveness of a CBR project. Using local resources is seen as an important element in ensuring that projects will be sustainable. To quote Pal, Das, & Sengupta (1998) *"a successful control policy has to be affordable, sustainable, acceptable and effective"*. They compared the costs of identifying children with epilepsy using a house-to-house screening and using Key Informants. Their overall conclusion was that using Key Informants is *"ultimately twice as cost effective"*. Jagannathan et al. (1993) assessed the costs of vocational training of leprosy patients by local craftsmen in the community. These are the only two articles explicitly dealing with the use of 'local resources'. Some authors included comments on the costs of their project. O'Toole (1988) for example, mentioned that the costs of the programme were 48 US $ per year per child, but not all costs could be included (e.g. costs for referral facilities). Maru & Cook (1990) calculated that the training of blind children in the community was half as expensive as training in a residential school.

Utilizing volunteers and other local personnel can also be seen as a means of using local resources. This has been covered under the key aspect 'stakeholders'. However, the costs of training, incentives, allowances, supervision, etc. are not elaborated and discussed in any of the articles on local or auxiliary personnel.

Participation

Only a few articles (five) were available on 'participation'. This is indeed surprising since 'participation' is at the heart of the definition of CBR (ILO et al., 1994). In a descriptive study, Pal et al. (2002) reported on the social activities of children with epilepsy. The other four studies are 'theory papers' discussing issues such as educational services for children with disabilities (Cavanagh, 1994), a community development approach (Ferrinho et al., 1993), attitudinal obstacles in accessibility (Peat, 1997a), and constructing ideas of community (Lysack, 1997).

Implementation

With representation in thirty-two articles, 'implementation' has been relatively well covered, and all types of articles can be found here, with the exception of 'intervention studies'. The descriptive studies (five articles) and the recommendations formulated for implementation of CBR projects were diverse. Coetzee & Kemp (1982) studied the needs and rehabilitation potential of discharged schizophrenic patients in order to implement programmes in the community. Utilization of services was researched by Hosain & Chatterjee (1998) and McConachie, Huq, Munir, et al. (2001). Although both concluded that economic problems affected attendance, McConachie et al. (2001) pleaded for a home-based approach that would more directly meet the needs of the mothers whereas Hosain & Chatterjee (1998) recommended linking a 'disability benefit allowance' to CBR to strengthen the economic position of people with disabilities. Boyce & Johnston (1998) discussed the collaboration between Community-based rehabilitation agencies. Finally, on the basis of their study on the mortality of young children with cerebral palsy, Khan et al. (1998) suggested that PHC and feeding programmes be included in intervention programmes. As discussed above, 'case reports' are a suitable method to describe the implementation processes of CBR. In general, the case reports included in this review are positive about the implementation of CBR. However, Stuelz (1999) argued that it is easier to integrate people with disabilities through educational programmes than within a PHC system.

The majority of the studies (eighteen articles) about implementation were theory papers. Eight articles debated the perceived benefits and potential of CBR (Cardenal, 1981; Gregory, 1996; Hai, 1993; Johnston & Tjandrakusuma, 1982; Kibria, 1989; Marincek, 1988; Mitchell, 1999a; Peat, 1991a; Thomas, 1992). Another six articles discussed different models that complemented and integrated the CBR approach (Jelsma et al., 1995; Miles, 1990a, 2002a, 2002b; Serpell, 1986). More fundamental changes to the CBR concept were proposed by Momm & König (1989). They stated that the existing models were professionally unsatisfactory, not self-sustainable, and relied on major back-up from outside the community. They then argued that rehabilitation is only one element of integrating people with disabilities in the community. Additionally, they believed that rehabilitation should be brought under the 'mainstream' of Community Integration Programmes. A parallel line of thinking was expressed by S. Miles (1996) when she argued that CBR should liase with disability right movements to ensure that CBR does not become just another way of providing services, but, through engaging in development issues, meets the different needs of people with disabilities.

Stakeholders

Different lists of stakeholders in CBR were compiled (Finkenflügel, 1998; Peat, 1997b). The discussion here is limited to the key stakeholders in CBR who are as follows: (1) people with disabilities, (2) families and family trainers, (3) the volunteers or Local Supervisors, (4) the Intermediate Local Supervisors or Rehabilitation Assistants, (5) the trainers, and (6) the specialists and project implementers. To accommodate all of the studies an extra category called 'other stakeholders in the community' was added. This, for example, included the study about the neighbours of families with a child with a disability (Bischoff et al., 1996). Studies about stakeholders have been categorised according to the type of study and to the specific

stakeholder. Three studies (Hartley & Wirz, 2002; Holloway, Lee, & McConkey, 1999; O'Toole & McConkey, 1998) have been entered for more than one of stakeholders.
Table 2.6 (page 41) illustrates how the 33 studies about stakeholders are divided over different stakeholders and different types of articles. Although the people with disabilities are described as the primary beneficiaries of CBR, only a few articles have been devoted to this stakeholder. In the only intervention study here, Powel, Mercer & Harte (2002) compared the 'Quality of Life' of people with disabilities receiving different (or no) rehabilitation services. Also, studies on the family and their perceived role in CBR were surprisingly limited. Although different authors were shown to be concerned about the role of parents, only Thorburn (1992, 1999) discussed this topic explicitly. Giacaman's (2001) paper was the only one in this review that presented a strong gender-specific view on CBR. She argued that expecting mothers to care for their disabled children would prevent them from taking part in economic life and that this would impoverish them even further.
With ten and thirteen papers respectively, the main interest in discussing stakeholders was regarding the Local Supervisors and the Intermediate Local Supervisor, thus addressing a core aspect of CBR. These two groups of stakeholders were introduced as essential cadres in developing rehabilitation services and are in fact positioned between the trainer and the person with a disability. This also implied a changing role for the trainers. This possibility was described in five theory papers. The specialists and organisations were discussed in one paper (Hartley & Wirz, 2002). Stakeholders in CBR will be discussed more thoroughly in chapter 4 of this thesis.

Project evaluation

The key aspect 'project evaluation' was the main area of interest in seventeen articles. Five of these were intervention studies covering the projects comprehensively (Mariga & McConkey, 1987; O'Toole, 1987), and three articles focussed on specific outcomes within a project (Finkenflügel et al., 1996; Lagerkvist, 1992; Lundgren-Lindquist & Nordholm, 1996).
Two descriptive articles described the development of an instrument to be used to compare different types of services (Beach et al., 1995; Evans et al., 2001). Lopez, Lewis & Boldy (1991) compared the actual services with the planned services and concluded that CBR indeed represented a low cost intervention system. Similar conclusions were drawn by three other studies. Menon (1984) stated that CBR through PHC is feasible and acceptable, Sharma & Deepak (2001) concluded that the CBR project evaluated had been successful on three of the five key components of CBR, and Gershon & Srinivasan (1992) illustrated that leprosy patients involved in CBR were better in repaying loans. A dissonant finding was presented by Rottier et al. (1993). In their study about client follow up, they found that, after initial identification, half of the clients were not seen again by rehabilitation workers. Consequently, for these clients the training had not even begun.
The only review paper about this key aspect was from Wirz & Thomas (2002). Their concern was that too few studies on the evaluation of CBR have been published and that those that have been published described practices rather than their effectiveness. They identified indicators that could guide CBR evaluations and make comparisons between projects possible. Similar work was done by Cornielje, Nicholls & Velema (2000, 2002). They proposed a classification system and identified indicators to be used to focus programme evaluations.

Table 2.6 Classification of studies on stakeholders

	Intervention	Descriptive	Case reports	Review	Theory paper
People with disabilities	Powell, Mercer & Harte (2002)				Hartley & Wirz (2002) Lysack & Kaufert (1994)
Families, family trainers			Thorburn (1992)		Thorburn (1999) Giacaman (2001)
Volunteers, Level Supervisors	Finnstam et al (1988)	Lysack & Krefting (1993) Rao, Venkatesan & Vepuri (1993)	O'Toole & McConkey (1998) Valdez & Mitchell (1999)	Chermak (1990) Wirz & Lichtig (1998)	Periquet (1989) Twible & Henley (1993) Holloway, Lee & McConkey (1999)
Other community members		Bisschoff, Thorburn & Reitmaier (1996)			O'Toole (1991)
ILSs / RAs	Dolan, Concha & Nyathi (1995)	Lorenzo (1994) Petrick et al (2001) Taukobong (1999)	Hartung, Kelly & Okamoto (1989) Maru & Cook (1990) Finkenflügel (1991) O'Toole & McConkey (1998) Thibeault & Forget (1997)		Bortz, Jardine & Tsuhle (1996) Holloway, Lee & McConkey (1999) Peat (1991b) Popovich (2001)
Trainers					McAllister (1989) Zinkin & Morley (1993) Kay, Kilonzo & Harris (1994) Holloway, Lee & McConkey (1999) Hill, McAuley, Sarchuk, & Shalom (1997) Hartley & Wirz (2002) Lysack & Kaufert (1994)
Specialists / Project implementers					Hartley & Wirz (2002)

2.5 Discussion

A few methodological constraints were encountered in compiling this review. These will be briefly discussed here.

- By rigorously clinging to the use of the term Community-based rehabilitation, articles published in the 1970s and early 1980s were not included although the descriptions were similar or close to the CBR concept. It can be argued that the term CBR was not yet familiar then and authors might have been uncertain whether the name itself was sustainable. Including these early articles would increase the number of articles in the first five-year period (Aptekar, 1983; Cardenal, 1981; Fernando & Mendis, 1980; Helander et al., 1980).
- Only studies on CBR in developing countries have been included in this review. In the past ten years an increasing number of articles on CBR have discussed services in developed countries (e.g. U.S.A, England, Rep. Korea, Hong Kong) (e.g. Aitken & Walker, 1987; Chermak, 1990; A. K. Clarke, 1987; Eldar, 2000; Freeman, 1997; Georgievski, 2000; Gregory, 2001; Hoeman, 1992; Kim & Jo, 1999; Kivelä, 1985; Kwok, 1995; Sandstrom, Hoppe, & Smutko, 1996). Some authors argued that comparative studies on CBR in developing and developed countries will probably reveal and highlight common principles and challenges (Hartley, 2001; Kendall, Buys, & Larner, 2000). However, in the above mentioned articles, CBR seen very much as an extension of the existing services offered in specialized institutions and, as such, their existence in society is believed to be quite different from CBR in developing countries.
- As discussed in the section on 'methods', a rigorous screening was done to determine which articles were to be included in this review. The consequences of excluding articles are not known. It can be expected that only a fraction of practical or personal experiences with CBR have been included since these experiences are not regularly published in the journals selected. The decision to only include articles from journals listed by PubMed has excluded the peer-reviewed journal 'The Asia Pacific Disability Rehabilitation Journal'. This journal has, in the last three years, developed itself into a forum for researchers and project implementers involved in rehabilitation in developing countries and the quality of the key articles is now comparable to articles included in this review. If a selection of articles from this journal were to be included in this review the number of articles in the last 5-year period would probably increase another ten to twenty articles.
- The coverage of this review is unknown. Clarke & Oxman (2003) argued that a search such as carried out for this review will reveal 30 to 80% of the articles published. However, it is believed that, because of additional searches and consultation with researchers in the field of CBR, the coverage is at least at the high side of this estimation (although a percentage cannot be given). If and how a full coverage would affect the findings remains uncertain.
- In this review chapters in (edited) books have not been included. These books are generally not peer-reviewed, but the quality of some of the chapters can be considered equal to a number of the articles included. A possible expansion of this review could include systematic assessment of chapters from these books.

The concerns expressed by Thorburn (1991), Lagerkvist (1998), Mitchell (1999), Wirz & Thomas (2002), and Miles (2003), and discussed in the introduction of this chapter, seem to

be addressed by researchers and practitioners interested in CBR. A steady increase in articles about CBR has been seen in combination with a shift towards publishing in indexed journals. Also, Thorburn's appeal for a forum on CBR appears to have been heard: two indexed journals (Disability and Rehabilitation, International Journal of Rehabilitation Research) have published 46 articles (or 40% of the total number of articles) on CBR.

This review shows that the articles about CBR cover a wide range of aspects of CBR in many developing countries. Although the increase itself might be satisfying, the breakdowns presented show that the articles available do not enable constructing coherent views about different key aspects of CBR or about CBR in different countries/regions. This is definitely impossible for aspects like 'local resources' and 'integration' as very few articles on these aspects could be found. Even for relatively well-covered aspects such as 'stakeholders' (33 articles), constructing a consistent view based on a meta-analysis of the articles is problematic since the available literature deals with different stakeholders in different countries that vary substantially in culture and socio-economic circumstances.

This review demonstrates that probably the only aspect that was covered satisfactorily is 'screening'. The IESCD studies presented evidence that the "Ten Questions questionnaire" is usable. Also, the advantages and disadvantages of house-to-house screenings and the use of key-informants were sufficiently discussed in several articles. Regarding CBR projects, it was concluded that the CBR projects in Guyana and Jamaica were the only ones described in different articles, at different stages, and that used different methodologies. As such these articles provide co-researchers with good insight into the project. However, the weak points of these studies might be that they have been conducted in a relatively small and confined area, and that the projects have been described by only one researcher, (respectively O'Toole and Thorburn) who were also the main implementers of the project.

In this review the types of articles have been matched with the key aspects of CBR. These key aspects were based on the 'research priorities' and the essential principles of CBR (Sharma & Deepak, 2001; WHO, 1988), and used in the study done by Mitchell (1999b). Different classes could also be considered to point out other characteristics of CBR that are otherwise somewhat disguised in this review. These classes cast light on possible gender inequalities in rehabilitation, differences in rehabilitation of children, adults, and the elderly, different needs and services for urban and rural populations, specific approaches to types of disabilities (due to cerebral palsy, leprosy, polio, schizophrenia etc.), types of rehabilitation (educational, vocational, medical), or to issues involving the set up of services and locus of control (including rights issues). Although approaching CBR studies through one or more of these topics would be interesting and worth doing, it is felt that the chosen set of key aspects provided a more comprehensive cadre for this review. As is already discussed above, it is possible to find more literature on the different key aspects if the literature is not linked to CBR per se. For example, in this review only two studies have been found regarding the use of local resources in CBR. Articles from other community programmes could be assessed in order to study local resources, costs, and cost-effectiveness, (Korte, Richter, Merkle, & Görgen, 1992; Valli, Ferrinho, Broomberg, Wilson, & Robb, 1991; Vos, Borgdorff, & Kachidza, 1980).

It is concluded here that the articles that could provide an evidence-base for CBR showed little coherency. Not only were key aspects insufficiently covered, but theory papers and descriptive

studies were not followed by intervention studies researching assumed relations and mechanisms.

2.6 Concluding remarks: directions for future research

In the introduction of this chapter Wirz &Thomas (2002) were quoted as saying: *"CBR has not developed sufficient published literature about planning, implementation, and evaluation..."*. The first challenge in CBR literature research is to review already published articles and make these available to researchers, project implementers, policy makers etc. The second challenge is to publish articles that will contribute to the evidence base for CBR.

Concerning reviews, two types of reviews are potentially interesting. The first is a broad review on a specific aspect relevant to CBR. For example, in studying the involvement of volunteers, not only articles on CBR should be reviewed but also articles on different development programmes (e.g. HIV/AIDS programmes, education for all). The second type of review includes chapters in books and 'grey literature' (newsletters, project reports, conference proceedings, annual reports, etc.). This 'grey literature' has a limited circulation and is seldom critically assessed. When its merits are judged consciously, this type of literature can be used in creating a more comprehensive view on specific aspects of CBR or in describing CBR in a specific country.

Although publications about CBR continue to be important in creating a knowledge and evidence base for CBR, it is feared that even doubling the number of articles will not be sufficient to perform a comprehensive meta-analysis on CBR due to its many different aspects. Up to now the majority of articles published about CBR are 'theory papers'. Although these have a distinct function in revealing underlying assumptions and processes, their use is limited unless complemented by in-depth case reports, descriptive studies, or intervention studies. Evidence for CBR can be built on the basis of practical experiences with CBR projects. Because of the inherent complexity of CBR, no one research study will be able to establish evidence for CBR. Instead of trying to establish a general knowledge and evidence base for CBR, it is probably more fruitful to ascertain evidence on specific aspects of CBR, and to study these in more controlled and experimental settings.

Appendix: List of literature included in the review

	Author(s) & year of publication	Type of article	Key aspect	Country
1	Amstel, v. Dyke & Crocker (1993)	Descriptive study	Screening	Papua New Guinea
2	Baolin & Huang (1999)	Case report	Implementation	China
3	Beach, Boyce, et al. (1995)	Descriptive study	Project evaluation	Nepal
4	Bischoff, Thorburn & Reitmayer (1996)	Descriptive study	Stakeholders	Jamaica
5	Bortz, Jardine & Tshule (1996)	Theory paper	Stakeholders	South Africa
6	Boyce & Johnston (1998)	Descriptive study	Implementation	
7	Boyce, Johnston, et al. (1997)	Case report	Implementation	India / Indonesia
8	Brodin & Molosiwa (2000)	Descriptive study	Knowledge	Botswana
9	Cardenal (1981)	Theory paper	Implementation	Nigeria, Mali etc.
10	Cavanagh (1994)	Theory paper	Participation	
11	Chermak (1990)	Review	Stakeholders	
12	Coetzee & Kemp (1982)	Descriptive study	Implementation	South Africa
13	Cornielje, Nicholls & Velema (2000)	Theory paper	Project evaluation	
14	Cornielje, Nicholls & Velema (2002)	Theory paper	Project evaluation	
15	Crishna (1999)	Case report	Implementation	India
16	Dolan, Concha & Nyathi (1995)	Intervention study	Stakeholders	South Africa
17	Evans, Zinkin, et al. (2001)	Descriptive study	Project evaluation	India
18	Ferinho, Robb, et al. (1993)	Theory paper	Participation	South Africa
19	Finkenflügel (1991a)	Descriptive study	Screening	Zimbabwe
20	Finkenflügel (1991b)	Case report	Stakeholders	Zimbabwe
21	Finkenflügel, van Maanen, et al. (1996)	Intervention study	Project evaluation	Zimbabwe
22	Finnstam, Grimby, Nelson, et al. (1989)	Intervention study	Stakeholders	Pakistan
23	Finnstam, Grimby & Rashid (1989)	Descriptive study	Screening	Pakistan
24	Gershon & Srinivasan (1992)	Descriptive study	Project evaluation	India
25	Giacaman (2001)	Theory paper	Stakeholders	Palestine
26	Gregory (1996)	Theory paper	Implementation	Polynesia
27	Grimby, Finnstam, et al. (1988)	Descriptive study	Screening	Pakistan
28	Hai (1993)	Theory paper	Implementation	Vietnam
29	Hai & Chuong (1999)	Case report	Implementation	Vietnam
30	Hartley (1998)	Review	Implementation	
31	Hartley & Wirz (2002)	Theory paper	Stakeholders	Nigeria / Uganda
32	Hartung, Kelly & Okamoto (1989)	Case report	Stakeholders	Pacific Basin
33	Hill, McAuley, et al. (1997)	Theory paper	Stakeholders	Solomon Islands
34	Holloway, Lee & McConkey (1999)	Theory paper	Stakeholders	six countries
35	Hosain & Chatterjee (1998)	Descriptive study	Implementation	Bangladesh
36	Ingstad (1990)	Theory paper	Knowledge	Botswana
37	Ingstad (1999a)	Theory paper	Knowledge	
38	Inthirat & Thonglith (1999)	Case report	Implementation	Lao
39	Jagnnathan, Ramamurthy, et al. (1993)	Intervention study	local resources	India
40	Jelsma, Cortes-Meldrum, et al. (1995)	Theory paper	Implementation	Zimbabwe

	Author(s) & year of publication	Type of article	Key aspect	Country
41	Johnston & Tjandrakusuma (1982)	Theory paper	Implementation	Indonesia
42	Kassah (1998)	Theory paper	Knowledge	Ghana
43	Katzenellenbogen, Joubert, et al. (1995)	Descriptive study	Screening	South Africa
44	Kay, Kilonzo & Harris (1994)	Theory paper	Stakeholders	Kenya / Uganda
45	Khan, Ferdous, et al. (1998)	Descriptive study	Implementation	Bangladesh
46	Kibria (1989)	Theory paper	Implementation	Botswana
47	Lagerkvist (1992)	Intervention study	Project evaluation	Philippines
48	Lopez Lewis & Boldy (1991)	Descriptive study	Project evaluation	Philippine
49	Lorenzo (1994)	Descriptive study	Stakeholders	South Africa
50	Lundgren-Lindquist & Nordholm (1993)	Descriptive study	Screening	Botswana
51	Lundgren-Lindquist & Nordholm (1996)	Intervention study	Project Evaluation	Botswana
52	Lysack (1997)	Theory paper	Participation	
53	Lysack & Kaufert (1994)	Theory paper	Stakeholders	
54	Lysack & Krefting (1993)	Descriptive study	Stakeholders	Indonesia
55	Mariga & McConkey (1987)	Intervention study	Project evaluation	Zimbabwe
56	Marincek (1988)	Theory paper	Implementation	
57	Maru & Cook (1990)	Case report	Stakeholders	Ethiopia
58	McAllister (1989)	Theory paper	Stakeholders	Zimbabwe
59	McColl (1997)	Theory paper	Other	
60	McConachie (2001)	Descriptive study	Implementation	Bangladesh
61	McConkey & Mphole (2000)	Descriptive study	Knowledge	Lesotho
62	Menon (1984)	Descriptive study	Project evaluation	India
63	M. Miles (1987)	Theory paper	Knowledge	
64	M. Miles (1989)	Theory paper	Knowledge	Pakistan
65	M. Miles (1990a)	Theory paper	Knowledge	
66	M. Miles (1990b)	Theory paper	Implementation	Afghanistan
67	M. Miles (1990d)	Theory paper	Knowledge	Pakistan
68	M. Miles (1993a)	Theory paper	Knowledge	
69	M. Miles (1996)	Theory paper	Knowledge	South Asia
70	M. Miles (1997)	Theory paper	Knowledge	Afghanistan
71	M. Miles (1998)	Theory paper	Knowledge	Pakistan
72	M. Miles (2002a)	Theory paper	Implementation	Afghanistan
74	M. Miles (2002b)	Theory paper	Implementation	Tanzania
73	S. Miles (1996)	Theory paper	Implementation	South Africa
75	Mitchell (1999a)	Theory paper	Implementation	
76	Mitchell (1999b)	Review	Other	
77	Mitchell, Zhou, et al. (1993)	Intervention study	Knowledge	China
78	Mitchell, Zhou & Watts (1989)	Descriptive study	Screening	China
79	Momm & König (1989)	Theory paper	Implementation	
80	Nordholm & Lundgren-Lindquist (1999)	Review	Implementation	Botswana

	Author(s) & year of publication	Type of article	Key aspect	Country
81	O'Toole (1988)	Intervention study	Project evaluation	Guyana
82	O'Toole (1987)	Theory paper	Project evaluation	Guyana
83	O'Toole (1991)	Theory paper	Stakeholders	Guyana
84	O'Toole & McConkey (1998)	Case report	Stakeholders	Guyana
85	Op-Heij, Dik, et al. (1997)	Descriptive	Knowledge	Jamaica
86	Pal & Chaudhury (1998)	Descriptive study	Knowledge	India
87	Pal, Chaudhury, et al. (2002)	Descriptive study	Participation	India
88	Pal, Das & Sengupta (1998)	Descriptive study	Local resources	
89	Palombi, Marazzi, et al. (1996)	Descriptive study	Screening	Albania
90	Paterson, Boyce & Jamieson (1999)	Descriptive study	Knowledge	
91	Peat (1991a)	Theory paper	Implementation	
92	Peat (1991b)	Theory paper	Stakeholders	
93	Peat (1997a)	Theory paper	Participation	
94	Periquet (1989)	Theory paper	Stakeholders	Philippines
95	Petrick, Sichangwa, et al. (2001)	Descriptive study	Stakeholders	South Africa
96	Pongrapai, Tayakkanonta, et al. (1996)	Descriptive study	Screening	Thailand
97	Popovich (2001)	Theory paper	Stakeholders	Botswana
98	Powell, Mercer & Harte (2002)	Intervention study	Stakeholders	Cambodia
99	Ran, Wen, et al. (1992)	Case report	Implementation	China
100	Rao, Venkatesan & Vepuri (1993)	Descriptive study	Stakeholders	India
101	Rottier, Broer, et al. (1993)	Descriptive study	Project evaluation	Zimbabwe
102	Serpell (1986)	Theory paper	Implementation	Zambia
103	Shah & Shah (2000)	Other	Other	India
104	Sharma & Deepak (2001)	Descriptive study	Project evaluation	Vietnam
105	Simeonsson (1991)	Theory paper	Implementation	
106	Stuelz (1999)	Case report	Implementation	Lao
107	Taukobong (1999)	Descriptive study	Stakeholders	South Africa
108	Thibeault & Forget (1997)	Case report	Stakeholders	Benin, Burkina Fasso
109	Thomas (1992)	Theory paper	Implementation	India
110	Thomas & Thomas (1999)	Theory paper	Project evaluation	
111	Thorburn (1991a)	Descriptive study	Stakeholders	Jamaica
112	Thorburn (1991b)	Case report	Implementation	Jamaica
113	Thorburn (1992)	Review	Screening	Jamaica
114	Thorburn (1993)	Theory paper	Screening	Jamaica
115	Thorburn (1999)	Theory paper	Stakeholders	Jamaica
116	Thorburn, Desai, Davidson (1992)	Descriptive study	Screening	Jamaica
117	Thorburn, Desai, Paul (1992)	Descriptive study	Screening	Jamaica
118	Thorburn, Desai, Paul, et al. (1992)	Descriptive study	Screening	Jamaica
119	Thorburn Paul & Malcolm (1993)	Theory paper	Screening	Jamaica
120	Turmusani, Vreede & Wirz (2002)	Review	other	

	Author(s) & year of publication	Type of article	Key aspect	Country
121	Twible & Henley (1993)	Theory paper	Stakeholders	Solomon Islands / Fiji
122	Valdez & Mitchell (1999)	Case report	Stakeholders	Philippine
123	Werrij, Voeten, et al. (2000)	Descriptive study	Knowledge	Jamaica
124	Whyte & Ingstad (1998)	Theory paper	Knowledge	Botswana
125	Wirz & Lichtig (1998)	Review	Stakeholders	
126	Wirz & Thomas (2002)	Review	Project evaluation	
127	Zaman, Khan, et al. (1990)	Descriptive study	Screening	Bangladesh
128	Zinkin & Morley (1993)	Theory paper	Stakeholders	

Notes:
[1] Healthlink: http://www.asksource.info/
[2] PubMed: http://www.ncbi.nlm.nih.gov/PubMed/
[3] PsychInfo: http://www.apa.org/psycinfo/
[4] CIRRIE: http://cirrie.buffalo.edu/
[5] Rehabdata: http://www.naric.com/search/rhab/
[6] Special thanks to M. Miles, B. O'Toole, A. Vreede, P. McLaren
[7] Miles: http://cirrie.buffalo.edu/bibliography/SAfricatoc.html
[8] i.e. Medical Library of the Erasmus Medical Center, Rotterdam
[9] Index Medicus: ftp://nlmpubs.nlm.nih.gov/online/journals/ljiweb.pdf
[10] Social Sciences Citation Index: http://www.isinet.com/isi/products/citation/ssci/
[11] Including its predecessor 'International Disability Studies'
[12] Palestine (Giacaman, 2001) is not on the World Bank list but it has been made part of this review
[13] IPSSCD: International Pilot Study on Severe Childhood Disability,
IESCD: International Epidemiological Study on Childhood Disability

Community-based rehabilitation (CBR): a programme in development

3

Abstract

The WHO introduced Community-based rehabilitation (CBR) in 1976 as a model to provide rehabilitation for people with disabilities in developing countries in 1976. In this chapter its development over the 25 years of its existence, and the main initial premises of CBR, are explored. Despite the practical experience gained within the programme, and the evaluation and research studies carried out, the relevance and cost-effectiveness of CBR are still under continuous discussion.

It is postulated here that in order to enhance the development of CBR, the underlying concepts should be explored, and insight into the motives of people involved in CBR and the interactions between these people should be obtained. A model of CBR, representing its structure and emphasising the different levels and types of input, interventions, and output, is presented here. This model functions as a theoretical framework in which the different elements of CBR, and the way they interact, are organised in a logical manner with the aim to make these relationships understandable and accessible for intervention, evaluation, and research.

3.1 Introduction

In chapter 1, the start of CBR was dated in 1976 with the publication of the document "Disability, prevention and rehabilitation" (WHO, 1976), but its development was really established with the circulation of the manual *"Training Disabled People in the Community"* (Helander, Mendis, & Nelson, 1980, 1983) and the evaluation of nine CBR pilot projects (WHO, 1982). By 1984, 40,000 copies of the manual had been distributed and the manual had been translated into 20 different languages (O'Toole, 1987). Although the approach was adopted by seven UN organisations in view of the "Decade of disabled persons", CBR stayed very much a concept bred and fed by the WHO. Apart from the official evaluation (WHO, 1982), only a few documents on these or other CBR projects were available during the first decade of CBR (e.g. Coetzee & Kemp, 1982; Johnston & Tjandrakusuma, 1982; Menon, 1984; Sebina & Kgosidintsi, 1981). Coetzee & Kemp used the term 'Community-based rehabilitation' without referring to the WHO programme and were probably unaware of it. The authors of the three other articles were involved in the evaluation of CBR. Concern and criticism were expressed even in the early years of CBR. Miles, who was also invited to the evaluation, circulated a paper entitled "Misplanning for disabilities in Asia" in 1981, but it was not formally published until 1986 (Miles, 1986, 2003). Despite the extensive publication of the manual and the support of the WHO, very little additional documentation, supporting or contrasting the findings of the evaluation, was available at that time. In fact, it took until 1985/1986 (10 years after the start of CBR) before articles and books on CBR to became readily available.

With the introduction of CBR, a different message was delivered to policy makers and rehabilitation workers in developing countries. This time the message was not that more professionals had to be trained and more resources had to be allocated to rehabilitation services, but that services had to be organised differently, i.e. by involving lay people and other kinds of rehabilitation workers. Not only did CBR pose a challenge to rehabilitation workers and other stakeholders, the concept itself was challenged. In the twenty years following the publication of the manual, rehabilitation workers involved in CBR used and tested the concept, attempted to clarify the relations between problems, interventions, and outcomes, and made an

effort to make the underlying assumptions explicit and researchable. CBR-programmes, commonly supported by Western donor organisations, were introduced in developing countries, CBR articles appeared in (inter)national journals, and the first books on CBR (or closely related approaches) were published (Marfo, Walker, & Charles, 1986; Thorburn & Marfo, 1990; Werner, 1987). At the same time rehabilitation workers and social scientists started an intense debate on the basic assumptions of the WHO-CBR programme and the findings of the evaluations (Miles, 1985; Momm & König, 1989; O'Toole, 1987; Serpell, 1986). Surprisingly, the most influential critics were not rehabilitation workers from the institutions who could have stood up to defend their concept of rehabilitation and their positions, but people who were deeply involved in CBR or CBR-like programmes. The growing interest of anthropologists (Burck, 1989; Devlieger, 1989a; Ingstad, 1990) in disability issues and rehabilitation services during this time could also be noted. They all shared experiences and, by doing so, contributed to the creation of a body of knowledge concerning the perceived problems of people with disabilities in developing countries, the way interventions could be set up and what kind of results should be achieved. It is most likely that the reported projects and published studies only reflect a fraction of the total number of projects since it can be assumed that many projects did not lead to (accessible) publications. Project reports are usually intended for informing governments or donor agencies and are generally not made widely available to others. Scientific research in CBR is even more rare. It is noteworthy that articles on CBR projects that are documented thoroughly are often written by researchers trained in the Western academic tradition. Notable examples are: Guyana Step for Step programme (O'Toole), Pakistan Peshawar Mental Health Centre (Miles), Jamaica 3D Projects (Thorburn), Mexico Project Projimo (Werner), and Zambia (Serpell).

There are no reports that the emphasis on CBR, and the support of the CBR concept by influential foreign donor organisations has actually lead to diminished support for, or even the closing down of, institutions. It seems that additional resources have been found and used to support CBR, and that CBR has been set up complementary to the existing institutional services. In fact, institutions and specialised centres themselves started some outreach and CBR programmes. As a matter of fact, CBR and Institution-Based Rehabilitation (IBR) services are, in these situations, part of the same system of support for people with disabilities. In Zimbabwe, for example, SIDA first funded rehabilitation departments in provincial and district hospitals and subsequently earmarked funds for outreach and CBR activities from these departments (Njini, Goerdt, Hanekom, & Lagerkvist, 1991). Concurrently with the expansion of CBR programmes, donor agencies and private benefactors (local and foreign) contrived to support institutional services for people with disabilities.

In this chapter a model of CBR will be constructed based on the initial documentation and manual of the WHO and the debate that took place over the past 20 years. This model could be used as a framework to develop a programme theory on CBR.

3.2 Relevance and cost-effectiveness of CBR

From the beginning, CBR has been a practical and pragmatic approach to caring for people with disabilities. The manual "Training people with disabilities in the community" (Helander

et al., 1983) as well as adjoining manuals (Helander, 1984; Mendis & Nelson, 1983), did not provide an explicit theoretical background for CBR. The basic assumptions for CBR are discussed in chapter 1 and presented in figure 1.1. This has lead to critical comments on the assumptions made and the presumed working processes. Two issues raised by criticisers of CBR appear to be of direct importance in constructing a programme theory: the relevance of CBR and the cost-effectiveness. These issues will be discussed in the following paragraphs.

3.2.1 Relevance

Throughout the discussion on CBR, the leading issue appears to be the many people with disabilities who are in need of – and entitled to - rehabilitation. Given the numbers of people to be rehabilitated and the resources needed, expanding institutional rehabilitation services to a scale where all people with disabilities could be assisted was not a feasible option. Whether or not institutions were able to equip people with disabilities with the right skills was also questioned because skills learned in institutional settings are not self-evidently transferable to life in a rural area or high-density suburb. A third problem that was recognised was that, in institutions, the knowledge and skills of rehabilitation stay with the professional rehabilitation worker and are not shared with family and community members.

However, perceived shortcomings of one system (IBR) do not legitimate other systems providing services (e.g. CBR). Alternative systems should not only formulate answers to a quantitative problem (the number of people with disabilities who have to be assisted), but should also come up with relevant answers to meet the needs of people with disabilities. CBR is promoted as a needs-generated or demand-driven approach. This implies that the self-perceived and self-defined needs of a person with a disability should guide the rehabilitation process. This needs-generated approach is often contrasted with a type of rehabilitation in which the availability of a certain type of assistance, the specific interest of an institution or programme, or the administrative procedures and standards will determine the aims and outcome of the rehabilitation process (supply-generated). It is also an important question if CBR programmes are by nature more sensitive to a needs generated approach than IBR programmes. According to Greenwood (1985), CBR programmes can still be characterised as supply-generated and are strongly based on concepts such as 'clinical disabilities', 'resource compensation', and 'individual improvements'. Rehabilitation, both IBR and CBR, is seen as 'an offer you can't refuse' more than an answer to the self perceived needs of people with disabilities. It can be argued that CBR and IBR are both supply-generated approaches, offering a type of rehabilitation that focuses on the impairments and disabilities of people and not on the physical and psychological barriers that hinder people with disabilities from participating fully in society.

CBR programmes appear to be tributary to the (original) commitment of organisations or Ministries. Programmes have been developed for certain age groups (e.g. children, the elderly), specific (medical) conditions (e.g. mental retardation, leprosy, cerebral palsy, epilepsy), or programmes with a strong emphasis on education or vocational training. These 'selective' programmes use, conserve, and expand expertise on a certain area of interest but tend to exclude people with disabilities whose needs do not fall within their expertise. The sensitivity of a programme to the needs of people with disabilities can thus be negatively influenced by

the expertise within the programme. In practice this problem is solved by referring people with disabilities to other programmes in the community or at district or provincial centres.

Generally, there is a huge information and knowledge gap between the rehabilitation worker and the person with a disability. This, combined with the difference in status and often social descent, makes it difficult for a person with a disability to voice his problems and needs. In addition, the absence of, or ignorance about, people with disabilities who have been successful in life makes it difficult for a person with a disability to picture herself with an ambitious future. Miles (1989, 1990, 1993) has argued extensively that a key strategy in rehabilitation is to make information on disability issues available. In his perception, the discussion on CBR and IBR focuses too much on the structures of how to provide rehabilitation services. His basic statement is that the use of information will enable people with disabilities, their caregivers and others who are involved, to solve many of the day-to-day problems associated with having a disability, with and without using formal rehabilitation services. If people have access to information about disabilities, medical interventions, possibilities for schooling and training, etc. they will be able to express, discuss, and negotiate their needs with people inside and outside the community and more effectively use services that are already there or being made available.

Anthropologists and disability activists have argued that CBR can only be a relevant approach if it matches the people's perception on a disability. Researchers have made an effort to reveal people's ideas on the causes of disability and determine their sensitivity to, and cooperation with, rehabilitation programmes (Burck, 1989; Devlieger, 1989a, 1989b; Kisanji, 1995). On the basis of 30 case studies, Burck distinguished three groups of people with disabilities. Only the people with disabilities with a 'liminal' position would benefit from CBR. The people with disabilities who were considered 'integrated' would be in a position to live their life in a way that was fairly equal to that of other villagers. Offering services to this group might even stigmatise them unnecessarily and be counter-productive. A third group comprised people with disabilities in a 'deviant' position. Their disability was blamed on their own mistakes or family problems. Without 'solving' these problems, a significant improvement in their function and position was considered hardly possible. She suggested that in some situations institutional care might be helpful.

The issue of 'traditional' beliefs versus Western rehabilitation models attracted a lot of attention from researchers and rehabilitation workers. This might be due to the interesting and 'exotic' aspects of the issue and to the perceived conflicting interests between 'traditional' and 'western-oriented' rehabilitation. Anthropological studies do provide insight into different views on disability that people might have, but they do not easily close the gap between the needs of the person with a disability and the expertise that can be offered by rehabilitation services. The expressed 'needs' are often not directly and causally related to the type and severity of a disability, nor can these needs solely be met by rehabilitation services. It should also be realised that needs-generated approaches have a strong normative aspect. Shared values on issues such as (in)equality of people, the position and responsibilities of individuals, families, communities, and authorities, and the use of available resources will determine the extent to which the needs of a person with a disability can be met.

'Relevance' and, in its footsteps 'needs-generated', appear to be complex criteria in evaluating the approach to be taken with a disabled person. It should be noted that any intervention by

rehabilitation services will change the circumstances and relationships between people and, by doing so, will influence the needs of the people with disabilities. If interventions change the life of a person with a disability more drastically (e.g. by giving him a special position in the community or by placing him in a rehabilitation institution) it can be assumed that the needs will change and will be related to his newly acquired special position, new environment, and new values.

If anything makes CBR a more relevant approach to the needs of people of disabilities than IBR, it is probably that the interventions of a CBR programme are supposed to take place in, and with the consent of, the community. Ideally, the values shared by the people in the community are respected and the community will integrate the CBR programme into their overall development. In this situation the frames of reference of a person with a disability, his caregiver, his family, or his community will include the expressed needs of a person with a disability, and this will in turn guide the rehabilitation process. While looking at the objectives of CBR programmes, it becomes apparent that objectives such as 'to increase awareness' and 'to change attitudes towards people with disabilities' are common. These objectives are not insensitive to the values in the communities. In fact, they aim at broadening, or even changing, the beliefs and values shared by the community members. In the end, CBR might be more interruptive than taking people with disabilities out the community to rehabilitate them somewhere else.

It can be concluded that the issue of 'relevance' is closely related to issues such as culture, values, etc. Both CBR and IBR introduce concepts that are developed in different (Western) cultures and traditions. O'Toole (1987) judges the first five years of CBR as a period of lack of progress. A main reason for this lack of progress is, according to him, the misunderstanding that Western skills, knowledge, and attitudes can and should be diffused into communities in developing countries. Several authors have stressed that rehabilitation should by addressing local realities and the needs of people with disabilities as perceived by themselves and the people they live with (Jaffer & Jaffer, 1990; Miles, 1985; Serpell & Nabuzoka, 1989). This approach might not match with ideas of professional standards, the sense of the righteousness of (Western) rehabilitation workers, and principles such as 'equal opportunities' and 'caring communities'. For example, convincing a family to spend time (and money) on their disabled child if the child will never be able to take part in household duties. Or, spending money on, and involving community members in, an income generating project for the few people in the village with disabilities when most of the adults in that same community are unemployed and can hardly generate enough income to support their own families. O'Toole (1989) argued that CBR as a theory is built on the understanding that family and community members are willing and have the capacity to train children with disabilities. In reality he saw that it was the mothers that the trained the disabled children while they were already overwhelmed with household and subsistence farming duties. In his mind, Community-based rehabilitation is very much 'mother-based' rehabilitation.

The WHO approach to CBR builds on the idea that people with disabilities, family members, community members, rehabilitation workers, and other people involved in rehabilitation have a common understanding of the problems of people with disabilities and share a common interest in solving these problems. Miles (1986) pointed out that, in reality, people tend to have

different ideas and expectations. The situation described in his quote that families *"...want a cure, not hard work"* will be encountered by many rehabilitation workers.

3.2.2 Cost-effectiveness

In the early stages of CBR it was argued that CBR it be far more cost-effective than other forms of rehabilitation (Mendis & Nelson, 1983). In order to discuss the cost-effectiveness of CBR, resources and outcomes for different forms of rehabilitation have to be defined and related to each other. In articles and programme reports the outcomes of CBR programmes are generally quantified by the number of clients involved in the programme, the functional progress of clients, the number of appliances given, the number of people attending a workshop, etc. Surprisingly, these studies very rarely account for the resources used in the programme and therefore analysing the relation between resources and results in the CBR programme becomes a difficult exercise. A comparison with other forms of rehabilitation is even more difficult. Comparable data sets are required to do this and these appear to be rare. Only a few studies are available that compare the costs of CBR and IBR. Berman & Sisler (1984) compared community-based services for blind people with institutional services and concluded that CBR is indeed less expensive. However, Momm, & König (1989) concluded that there is no evidence that CBR is more cost-effective than rehabilitation or training in institutions. Thus, the claim that CBR is more cost-effective than other forms of rehabilitation is still unproven.

IBR is believed to be expensive because of the finances needed to build, maintain, and run rehabilitation departments, residential homes, or specialised centres, and to purchase equipment, to provide meals for the residential clients, to employ household staff, etc. It is argued that if the finances used for IBR are instead used for CBR, many more people with disabilities can be supported and the costs of rehabilitation per person through CBR will only be a fraction of the costs of rehabilitation in institutions. At least three problems arise in comparing or 'benchmarking' these two types of rehabilitation.

First, it appears to be difficult to calculate the full costs of IBR and CBR. Budgets and annual accounts give information on the direct expenditure of a programme. In a closed setting like a rehabilitation centre, vocational training centre, special school, etc. the annual accounts and reports will give a good idea on the earnings and expenses of a centre. Calculating the costs of a rehabilitation department (as part of a hospital) is already becoming more difficult since many costs (e.g. salaries of doctors, hospital administration, running costs of buildings) will not be linked to the rehabilitation programme. This counts even more for CBR. By nature, CBR uses resources existing in, and directed towards, the community. In CBR the input of nursing staff, staff from other health programmes (e.g. Council for the blind), staff from different community development programmes (e.g. Environmental Health Technicians, Village Community Workers), teachers, Social Welfare officers, and the use of (specialised) personnel in referral centres is not reflected in the budget and expenditures of a programme. Institutional and community-based services appear to develop complementarily to each other. In the Zimbabwe CBR programme, two-thirds of the clients identified in CBR were also referred to the hospital or other specialised services, including institutionally based services (Ministry of Health, 1990; Rottier, Broer, Vermeer, & Finkenflügel, 1993). CBR programmes also make use of existing facilities (e.g. such as places to hold workshops, cars, overnight accommodation)

without being charged for it. The budget of a CBR programme thus only reflects part of the expenses made to assist people with disabilities in the community. It is debatable whether or not these 'invisible' costs should be linked to the CBR programme since they can be seen as a regular use of health and other community facilities. However, CBR can hardly be labelled as an inexpensive programme. The costs of training of rehabilitation workers, intermediate level supervisors, local supervisors and volunteers, in addition to the salaries and incentives, the workshops in the community, and transport account for substantial costs, which need to be covered. These costs are illustrated by the following example from CBR projects in Zimbabwe. In Zimbabwe, the total costs of the training workshops which were held at the start of each of the eight CBR pilot projects of the Ministry of Health were 75.000 Z$ or app. 35.000 US$ (Ministry of Health, 1990). The salary costs of rehabilitation staff still have to be added. These are estimated to at least 25.000 US$ (salary costs of civil servants, teachers, social workers, nurses, or others involved in the workshops that were not registered). The total costs for workshops were at least 60.000 US$. The eight pilot projects resulted in the identification of 1614 people with disabilities who could benefit from rehabilitation. This implies that 37 US$ is spent on the identification of one person with a disability (as a comparison: the minimum wage by that time was app. 70 US$ a month, a Rehabilitation Technician earned app 350 US$ a month). Costs for follow-up visits, instruction of family members and volunteers, referral to specialist services, or appliances are not yet included.

Secondly, it is not evident that the results of different rehabilitation programmes are comparable. In IBR, the results will mostly focus on the functional progress and independence of individual clients. In CBR, these outcomes will be complemented by outcomes that concern the family and the community as well (e.g. increased awareness, change of attitude, appreciated position in the community for people with disabilities). In order to compare the results of different types of rehabilitation, their conditions and results have to be standardized. This might work in some specific programmes (e.g. people who are visually impaired and are engaged in mobility training), but real methodological problems are encountered if the type and severity of disability differ greatly (such as with people with cerebral palsy). Functional assessment scales that can be used to evaluate the progress made by a person with a disability have been developed, but comparative studies of people with disabilities trained in institutional settings or trained in the community using these scales are not known.

Thirdly, both IBR and CBR seem to have their own financial streams (often from organisations or persons with a specific affinity to the centre or programme) which are often not used for regular running costs but for projects, or to support individual people with disabilities (e.g. training course, appliances). Many CBR programmes are specifically funded by (inter)national organisations concerned with people with disabilities. Thus competition with immunisation programmes, HIV/AIDS programmes, water and sanitation programmes, etc. is being avoided and discussions that encourage involvement with CBR can be held at the community level without bothering with the financial consequences too much. It is doubtful whether this is still 'real' CBR since resources for CBR in this case would come from outside the community. The other side of the coin is probably that the people with disabilities in this situation are often disadvantaged people who are not yet involved in community organisations and are not involved in decision-making processes in the community. In situations where the needs of

people with disabilities are not voiced or recognised, resources that are not specifically earmarked for CBR will probably be used for other community development programmes. Whereas the advantages of using outside resources might be obvious, so are the disadvantages; ownership of the programme can easily be held by the donor organisation and not the community. Therefore, the programme will be vulnerable to decisions by, and policy changes of, the donor organisations.

The main expenses of a rehabilitation programme are the salaries of staff members. In CBR, community members are expected to be involved as volunteers and Local Supervisors (LSs). By introducing volunteers and LSs, it is assumed that (expensive) professional rehabilitation staff can impact many more people with disabilities than would be possible in a clinical setting. The LSs are trained and supervised by professionals at the district level (the intermediate level supervisor (ILS)) (Helander, 1993, 1999). An ILS can be a nurse, social worker, teacher, therapist or rehabilitation assistant. According to the 'CBR delivery system', an ILS will be responsible for a district with a population of 50.000 to 100.000. If it is assumed that 1.4% to 2% of the population is, at any time, in need of rehabilitation, the ILS will (indirectly) be involved with 700 to 2000 people with a disability.

Using the caseload of a rehabilitation worker as a measurement for efficiency is a questionable exercise, especially if one wants to compare institutional and Community-based rehabilitation. We do not have a good estimation of the number of clients assisted by rehabilitation workers in the different settings. These settings are very different from each other (e.g. rehabilitation department in a hospital, vocational training centre, special school, outreach programme), and we do not know if the type of services offered are comparable. Figures from hospitals will, for example, include post-operative patients who have, for example, been seen once or twice to help them with cleaning their lungs, or patients who needed a short instruction on how to use crutches. On the other hand, information and instructions given to family members, volunteers, and ILs will not only benefit one specific client but will hopefully raise the knowledge and awareness level and thus benefit others.

The claim that a rehabilitation worker in CBR is able to assist 700 to 2000 people with disabilities should be discussed given the often difficult circumstances in developing countries. The ILS should be able to use transport to go to training sessions, meetings, and to give advice concerning the training of people with disabilities who have been referred to her by the volunteers or LSs. Transport in developing countries (i.e. in rural areas) is time consuming, and the use of public transport will not permit the ILS to follow a tight schedule. Private transport is expensive, and the maintenance of motorcycles and cars is an ongoing problem.

3.3 Trends in rehabilitation

After 1994, the discussions about the correct use of the term CBR (see chapter 1), and its relevance and effectiveness continued, but the tone changed and became milder. While reviewing this discussion, it is concluded that the basic ideas of CBR have been questioned extensively and that evidence to support the promises, advantages, and claims of CBR is still scarce. In an apparent attempt to reconcile with some of the critics on 'his' CBR concept,

Helander (1993) argued that the CBR-approach should not be used as a blueprint and that rehabilitation workers should adapt CBR to the local circumstances. However, at the same time he stated, *"Projects or programmes that do not apply the basic principles of CBR, on the other hand, should use another term to describe their activities"*. The suggestion which can be derived from this statement is that there is a set of principles or a checklist that can be used to distinguish 'real' CBR from other activities. Interestingly, Helander (1993, 1999) does not provide such a set in his extensive introduction to CBR. Also, by giving examples of projects and rehabilitation of people with disabilities all over the world, he strongly suggested the universal validity and applicability of CBR.

The 'joint position paper' (ILO, UNESCO, & WHO, 1994) and the new definition are probably representative for the development of CBR after 1994. The fierce criticism faded and articles and books on CBR described and evaluated programmes in a more equable and generally positive way. Regardless, some rehabilitation workers are still willing to debate the principles of CBR. For example, Vanneste wrote *"...CBR programs are more of a normative demand than a practical concept for the provision of services to people with disability"* (Vanneste, 2001). However, this type of discussion has become rare. In fact, CBR does not seem to get the attention it used to get. Two explanations can be given for this. First, this might be due to the fact that all arguments have been exchanged extensively and CBR is no longer contested with the new definition widely accepted. Articles on the implementation and evaluation of CBR programmes are still rare in scientific journals although some cross-cultural studies on disability and rehabilitation are being published regularly (Holzer, Vreede, & Weigt, 1999; Leavitt, 1999; O'Toole & McConkey, 1995; Peat, 1997). Second, it might be that people in developing countries do not have easy access to facilities in which to do research and cannot spend time to set up systematic research, analyse data, and work on publications (Wolffers, Adjei, & van der Drift, 1998). Additionally, even if research in CBR were conducted, it would be difficult to meet the standards set by (Western) scientific journals. For example, controlled circumstances, working with control groups, and testing people on a regular basis would be difficult to organise in a developing country.

Although the debate on CBR became less pronounced, different issues on CBR have emerged or become more visible in the discussion. Four emerging trends in rehabilitation were distinguished in a United Nations publication (1996): human rights, expansion of CBR, standard terminology and demand for information. These trends are discussed here briefly.

3.3.1 Human rights

In 1994 the United Nations published 'The Standard Rules on the Equalization of Opportunities for Persons with disabilities' (1994). In this document, it was emphasized that people with disabilities experience the consequences of a disability when they relate to other people or when they are in an environment that limits them in their functioning. Interventions generally aim at improving relations with other people (awareness raising) or in making changes in the environment to ensure that people with disabilities have equal access to services, school, work, sports, information, etc. Whilst the rights of people with disabilities have been formalised and are ready for implementation at different levels in society, disability activists have started claiming their rights and control over programmes for people with

disabilities and organisations that are involved with 'disability issues'. For them, it is no longer acceptable that services aiming to improve the life of people with disabilities are in the hands of able-bodied people. People with disabilities have argued that in CBR (as in all types of rehabilitation, vocational training, special education, etc.) they are still seen as beneficiaries and not as people who are in control of their own rehabilitation process and who are able to take full responsibility in society. Disabled People Organisations (DPOs) and Independent Living Movements (ILs) have in some CBR programmes liaised with rehabilitation workers and advocated for a strong position of people with disabilities in programme management, programme evaluation, and research (Cornielje, 1993; Lysack & Kaufert, 1996; S. Miles, 1996).

3.3.2 Expansion of CBR

As discussed above, CBR can no longer be considered a preset and inflexible approach but is more like an umbrella under which a diversity of rehabilitation programmes in the community can be sheltered. Or, to quote Miles here: *"We began with CBR as an idea. In fact CBR is a bag of ideas"* (1994). Now that it seems to be accepted that differences are not a threat to CBR but a reality, a classification or taxonomy of CBR programmes is useful. Classifications can be made based on the aims, structure, human resources, and origin of CBR programmes (McColl & Paterson, 1997; Peat, 1997). An attempt to conceptualise and visualise different CBR programmes was made by McColl & Paterson (1997). In their model, programmes are described using six dimensions. Three dimensions (ranging individually vs. community oriented) define the programme: aims/mission, beneficiaries, and strategies. The other three dimensions (ranging from inside vs. outside community) support the programme: human resources, structural resources, and attitudes. Their model results in two cubical structures with eight sections each and, in theory, allow 64 different combinations. A similar exercise was undertaken by Cornielje, Nicholls & Velema (2000, 2002). They classified CBR programmes on four dimensions: expected outcome of interventions, locus of power, commitment to involve others, and services. The range is divided in three: from an individual model to a social model. With 12 boxes, 81 combinations are possible.

Both groups of researchers claim that their model will assist in evaluation, research, and communication about CBR, but they have not yet provided evidence of extended use of these classification systems. Probably the most important gain at this stage is that recognising the differences between programmes ensures that programmes are not too easily compared with each other and are not too easily judged on inappropriate criteria. It also ensures that the expansion of CBR will happen along different lines, depending on specific situations and local needs.

3.3.3 Standard terminology

Not only has the term CBR been under continuous discussion, but the terminology used to classify the consequences of impairment has also been disputed. The triple term 'impairment, disability, handicap' has been used in CBR programmes (Grimby, Finnstam, Nelson, & Rashid, 1988). This classification has been revised and changed into 'body structures, functioning, participation' (WHO, 2001). Although the need to have a common understanding on the terminology used is understood, it is not discussed further in this thesis.

3.3.4 Demand for information

Probably the most emerging trend is the demand for information. The key issue in CBR projects is now 'accountability', and this is associated with terms like transparency, evidence-based, effectiveness, efficiency, etc. Several authors have argued that further developments of the CBR concept, and expansion of programmes, depend on the ability to generate data on the outcomes or impact of CBR. Fifteen years after O'Toole complained about the lack of progress in CBR (O'Toole, 1987), Wirz & Thomas (2002) – observing that, in the fields of health and education, different systems and standards have been established to evaluate programmes – concluded: *"However, Community Based Rehabilitation (CBR), being a relatively young field with poorly defined processes and performance indicators, currently lacks these systems and standards"*. At a symposium in 2002 Thomas pointed out that CBR is in danger of fading out if no hard figures on the results of CBR can be presented to policy makers, funding organisations, etc. (Thomas, 2002).

A consensus in CBR has been reached more by accepting the differences more than by standardising CBR approaches. This consensus has culminated in a plea for information. In the (short) history of CBR, information has been mainly collected for evaluation purposes and focused largely on the outcomes of CBR projects. This, and the shortcomings of this type of information, will be discussed in the next section.

3.4 A programme with learning problems

Figure 1.1 (page 6) presented a uni-dimensional approach to meeting the needs of people with disabilities. Problems were defined as personal disadvantages in addition to the limited resources the society has to solve these problems. Interventions in CBR did not aim at decreasing these quantitative limitations but at involving other people in the rehabilitation process. The outcomes of CBR focussed on an efficient use of resources and the functional progress of people with disabilities. Although this type of information can be collected in a reasonably straight forward manner, its value is difficult to assess since these studies generally suffer from a number of methodological problems (i.e. there is no baseline, no correction for natural growth, no control groups, and a high rate of defaulters or non-traceable clients). Wirz & Thomas (2002), amongst others, have argued that the lack of accepted evaluation instruments hinders a meta-analysis of CBR programmes and therefore leaves the claims of CBR unproven and disputable. Whilst evaluating projects is definitely useful, the merit of such exercise is limited with regards to the theory building and conceptualisation of CBR.

CBR projects were implemented to help people and not to serve as research studies. Using quantitative experimental research designs in the implementation and evaluation of a CBR project will make the project less flexible. In such projects the different people involved in CBR are very much limited in the adaptation of the programme according to their needs and perceptions. Miles (1991) argued that in Pakistan 'rigorous scientific research' is hardly feasible because of the absence of elementary baseline data, research assistants, and access to libraries and databases. He also questioned the relevance of this type of research and argued that to understand the complex, and changing, interactions between people and their social

environment, qualitative research is needed. He stressed that *"methodology should be within the researchers' capacity and likely to produce meaningful results"*. Action-oriented studies, mini-surveys, and reported observations provide knowledge relevant for planners and professionals and generate an on-going movement towards policy development and service provision.
Several other authors have argued that more qualitative research is needed to understand the rehabilitation process in CBR. According to O'Toole (1988), there is a danger *"...that evaluation focuses only on what can be readily measured and more intangible feelings such as increased hope, improved relationships with others and self satisfaction, are overlooked"*. In his evaluation of a CBR programme for pre-school children in Guyana, he used standardised development tests to assess the children's progress. However, he also added that *"quantitative gains need to be balanced with a qualitative analysis of the process involved"* and included self-rating scales to measure changes in the attitude of the mothers as a result of the child receiving treatment and to measure parental disappointment concerning their disabled child.
In line with earlier work done on streamlining information (Boyce & Ballantyne, 2000; Boyce, Broers, & Paterson, 2001; Cornielje et al., 2000) Wirz & Thomas proposed the development of a set of indicators to be used in the evaluation of CBR programmes. Their work very much focused on those stakeholders who are involved in programme planning and who are accountable to (donor) agencies, policy makers, or governments. The explicit promise in this article was that a widely accepted and used set of indicators would permit meta-analysing rehabilitation programmes (across the different approaches) and that results can be used to convince policy makers (Cornielje, 1999; Wirz & Thomas, 2002). In some studies long lists of unsorted indicators are compiled whereas other studies have tried to group indicators in domains representing the main issues or dominant perspectives of CBR (Cornielje, Nicholls, & Velema, 2000; McLaren & Philpott, 1999; Wirz & Thomas, 2002). Wirz & Thomas (2002) presented a literature review on the need for, and the use of, indicators to measure the effectiveness of CBR programmes. They state that *"the field is criticized as having poor indicators with which to measure success"* and conclude that *"robust and easy to use"* indicators need to be developed. In view of the discussion in this chapter, it can be added that it is not only the absence of 'success measurements', but, most of all, the lack of consistent theory building that hampers a meta-analysis and further development of CBR.

3.5 Developing a programme theory for CBR

In a simple form a rehabilitation process involves only a few stakeholders. Generally these are a person who was never able to, or no longer, meet her own expectations due to a disability and a trainer (e.g. teacher, therapist, social worker) offering assistance. Goal setting in rehabilitation depends on the expectations of the person with a disability and the skills of the trainer. Trainers can, on the basis of previous experiences and research, outline the abilities that can be (re)gained and discuss this with the person with a disability. If the person with a disability agrees to the treatment, the amount of time, energy, and often money she wants to devote to it, and how much the trainer can invest, should be discussed between them. This process is relatively simple since it basically involves only two stakeholders. Sometimes the person with a

disability is not able to make a decision or to express her needs (e.g. people with mental illness or people with severe communication problems). In these situations close relatives of the person with a disability must be consulted, and they often make decisions regarding the required intervention.

As represented in figure 3.1, this basic type of rehabilitation is a one-directional model consisting of someone who needs help and someone who is able to assist. The goal of the trainer's intervention is to promote changes in the person with a disability. Additionally, changes in the direct physical environment of this person can be engineered in order to make it possible for her to (re)gain her position in the community. In this model, research will mainly focus on the causes and progress of the disabling condition, and the effectiveness of the intervention (generally measured as functional progress of the person with a disability).

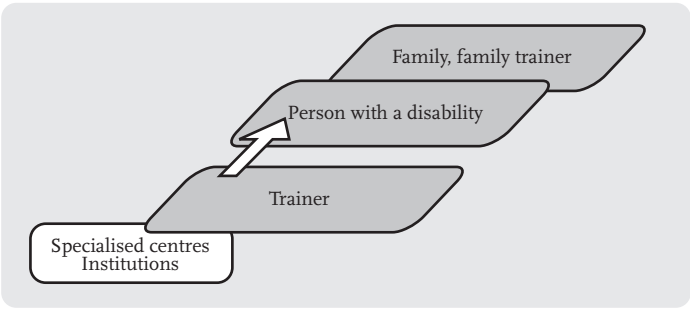


Figure 3.1 One-directional representation of the rehabilitation process

In the CBR model, a more differentiated and complex network of stakeholders is formed. The heart of the CBR programme is what Helander describes as the 'CBR delivery system' (1993, 1999). In this system, the different stakeholders are positioned like roofing tiles and the relations between them can be modelled according to the example given in figure 3.2.

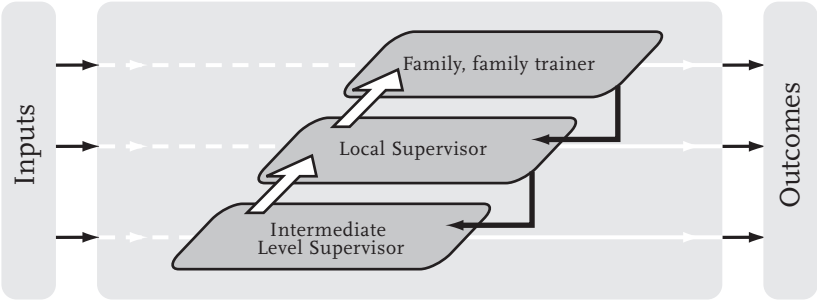


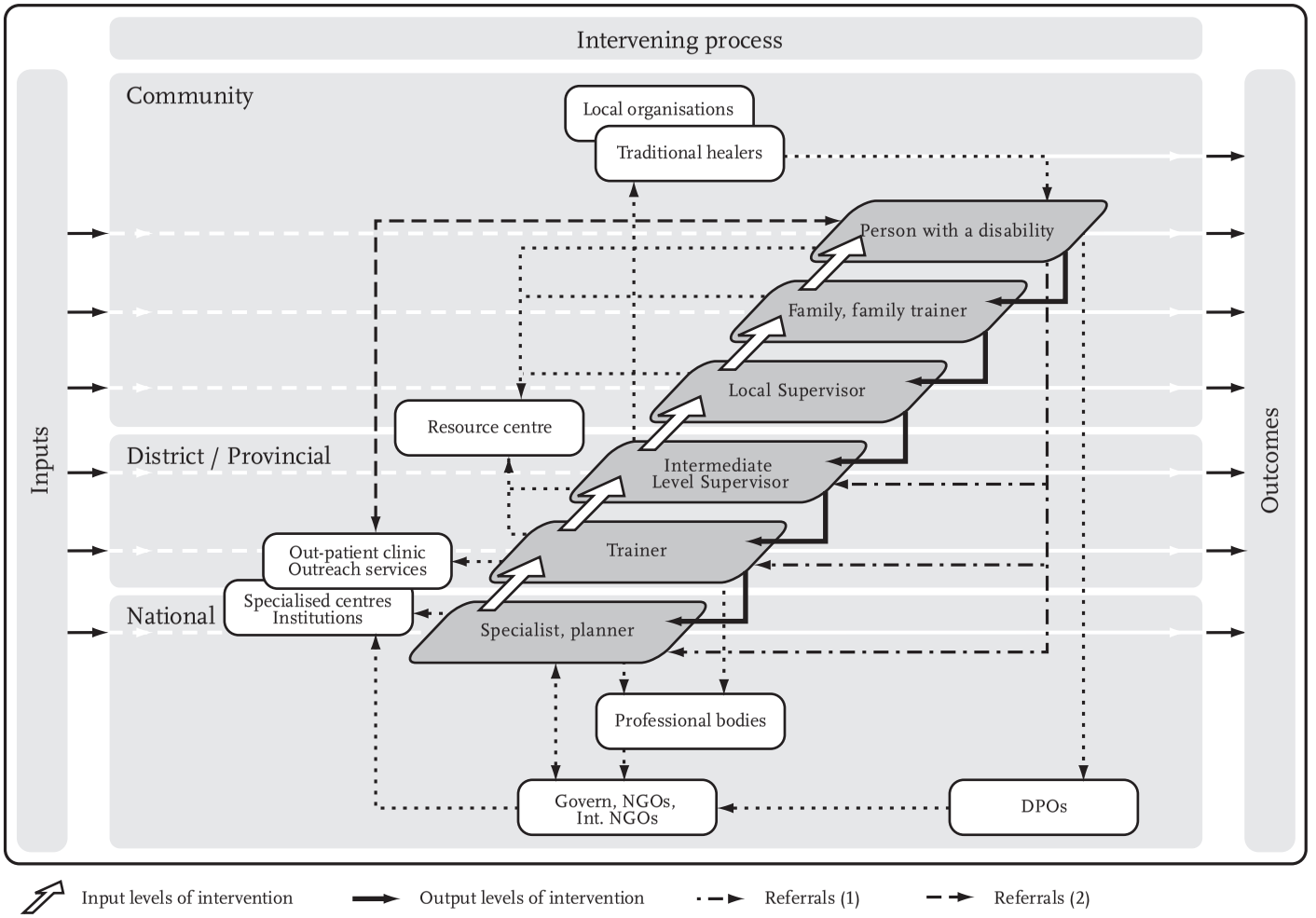
Figure 3.2 Schematic representation of the intervention at stakeholder level in CBR

Every stakeholder can be described as a level of intervention in which the input and the expected outcomes can be defined. Because of the roof tile construction, the outcomes of

intervention at the level of one stakeholder will overlap onto the next level. As such, CBR can be described as a chain of intervention levels that are highly dependent on each other. 'New' stakeholders were introduced into the process as an instrument to make rehabilitation available to many more people with disabilities than in the conventional model. This can be illustrated using a mathematical example based on Helander's model (Helander, 1993). He foresees a situation where one trainer supervises thirty Intermediate Level Supervisors (ILS), every ILS supervises twenty Local Supervisors (LS), and a LS supports ten family trainers. In such a situation, 6,000 people with disabilities are, at any time, indirectly assisted by one trainer.
The involvement of these different stakeholders is represented in figure 3.3 (page 67). Like other representations, this scheme is a reduction of reality. Interactions will not always exist neatly from one stakeholder to the 'neighbouring' stakeholder. For example, a mother may decide to take her child with a disability to a hospital without consulting the family trainer and the Local Supervisor, or the trainers at the provincial level might prefer to educate the Community Rehabilitation Workers directly, or project evaluators may want to contact the people with disabilities directly. In addition, interactions do not only take place between different groups of stakeholders but also within groups of stakeholders (e.g. people with disabilities who meet and form support and advocacy groups, parents who join together in Parents Associations, and trainers and other professionals uniting in professional organisations). All of these groups will have their own goals and agendas. Another limitation of this model is the number and grouping of stakeholders. More stakeholders could be added. These would be, for example, local and national governments, donor organisations, researchers, or the private sector. Stakeholders also can be left out. In some CBR projects the Local Supervisor and Intermediate Level Supervisor are not seen as different stakeholders. For example, in Zimbabwe the Rehabilitation Technicians (comparable to Intermediate Local Supervisors) work directly with family trainers and people with disabilities (Finkenflügel, 1991; van der Hulst 1993).

As discussed before, outcomes of CBR are generally evaluated only at the level of the person with a disability. However, his model illustrates that in a full-blown CBR programme, inputs, interventions, and outcomes at all six levels should be defined. Not only do different levels require different types and intensities of input, but the effect of the intervention will be different due to differences in education, perception of the situation to be changed, power to make changes, etc.
In CBR, the input at each level can generally be described in terms of education and training. The expected outcome is an increased competency to train the next level. It is only in the intervention level 'person with disability' that the sought outcomes are often information on mobility, independency, quality of life, etc. The outcomes of one level are also used as input, usually for the underlying level.
The model does not, for practical reasons, include the uncontrolled inputs and unexpected outcomes, but it does relate the levels of intervention (as defined in CBR) to IBR services. As discussed above, IBR and CBR are often part of the same support services for people with disabilities. DPOs are also included as representing the 'human rights' approach to CBR. In the model, they are seen to influence governments and national organisations. However, it should

Figure 3.3 A model of CBR



also be realised that DPOs and other pressure groups do influence policymakers at the local, district, or provincial level. Professional organisations of, for example, therapists and their influence on national policies, manpower planning, etc. are also included in the model.

To complicate the model even further, it is important to realise that CBR never takes place in a laboratory situation and uncontrolled inputs and unexpected outcomes will be part of any programme. These unexpected outcomes can also be due to of a limited understanding of the intervention.

A dominant part of the model presented in figure 3.3 are the bars on both sides. In fact, CBR is perceived as a complex intervening process in which inputs (bar on the left) and outcomes (bar on the right) can be defined. A programme theory about CBR should be based on a theoretical understanding of the interventions at the different levels. Because of the interdependency of these levels, the effectiveness of CBR will depend highly on effective interventions at each level and on the extent the different levels can be linked to each other. Subsequently, understanding CBR and interpreting the results of CBR programmes starts with an analysis of the inputs, intervening processes, and outcomes.

This model has the potential to be used to interpret the findings of CBR evaluation and research studies. The information generated will improve the effectiveness and conceptualisation of interventions and thus contribute to the validation and further development of the programme (Harachi, Abbot, Catalano, et al. 1991). The model will be especially useful in directing evaluation and research studies. By postulating and explicating the relation between inputs, intervening processes, and outcomes from the beginning, the findings of research can then be used to define the strengths and directions of relations and consequently contribute to the theory of CBR. It should be pointed out that the model presented is not fixed and should be adjusted on the basis of research findings.

Who is in ...and for what? An analysis of stakeholders' influences in CBR

4

Abstract

CBR builds on the active involvement of people with disabilities, volunteers, community rehabilitation workers, trainers, planners, and policy makers and can therefore best be viewed as a 'web of interactions' between and among these people. To explore the roles of the people involved in the processes of CBR, a stakeholder analysis is being used. In this analysis different stakeholders in CBR have been identified and their position and influence in the process has been anticipated. This type of analysis sheds light on the processes of CBR and, consequently, makes them accessible for research. It also allows developing strategies to get the most effective support from the stakeholders involved.

The relevance and efficacy of the different stakeholders will, to a large extent, be defined by the requests and expectations of the other stakeholders involved. In order to assess the stakeholders, a normative framework which includes not only the position and competency of the different stakeholders, but also their decision-making capacities and information needs, was constructed.

4.1 Introduction

Nickols (2000) used the term 'nexus of contracts' to describe the relations between and among the various stakeholders. Although in CBR, stakeholders will most likely not label their relationships as based on 'contracts', and these are probably better described as based on 'expectations' - the term covers the process of CBR nicely. Nickols further elaborated that *"the success of an organization is a function of the extent to which the needs and requirements of its stakeholders can be integrated and balanced, without scarifying any one to the other"*. The interdependency of stakeholders, including key elements such as mutual influence and accountability, is crucial in working with this concept.

A basic stakeholders analysis will take three steps (MSH-UNICEF, 1998):

1. Identify stakeholders:
   This includes listing the different stakeholders and a description of what they actually do.
2. Anticipate the kind of influence they have:
   Most importantly, here is how much power each stakeholder has on the organisation, what the needs and expectations are of the stakeholders, and how these can be satisfied by the stakeholder themselves or by other stakeholders involved.
3. Develop strategies in order to get the most effective support.
   Th*is strategy should match the competencies and positions of various stakeholders to influence the organisation. It includes training, supervision, information, etc.*

What stakeholders actually do (step 1 of the analysis) can be described as a series of actions or interventions, for example, demonstrating exercises to family members, discussing the impact of having a disability with community leaders, instructing village community workers, or educating trainers. The effects of all interventions made by the different stakeholders are believed to reflect an improvement in abilities or a change in the position of the person with a disability. However, the interventions themselves, the involvement and compliance of the stakeholders, and the effects on the different stakeholders are seldom analysed. For example, it is not clear if and how increased knowledge about disabilities changes the stakeholders' attitude

towards people with disabilities, or makes her more competent to fulfil her role in the rehabilitation process. Nor is it self-evident whether or not an increased ability of a person with a disability is due to increased knowledge or competence of family or community members.
A study done by O'Toole in Guyana showed that the reactions of mothers to a parental involvement programme were very different and often depended on the various responsibilities the mothers have (O'Toole, 1989). He concluded that *"Future research could usefully investigate the variables within the child, family and community which may contribute to the effectiveness of the programmes"*. Hereafter, a short discussion on the different stakeholders as found in the relevant literature is presented.

4.2 Stakeholders in the community

The most prominent stakeholders in the community are the person with a disability, the family / family trainer, and the Local Supervisor. However, they are not the only ones. More stakeholders can be identified in the political and administrative system (e.g. administrators, council members, civil servants), in the informal health system (e.g. traditional healers, traditional birth attendants), educational services (e.g. teachers), and in the local business community (e.g. shopkeepers, craftsmen, credit scheme holders). In general, they will be 'latent' stakeholders, meaning that they become involved when a specific issue is raised.
In CBR literature, traditional healers are often included in the CBR process, as it is believed that many of the people with disabilities who get involved in CBR are also looking for help in the traditional care system. In addition, the general public or 'the community', is addressed with regards to (perceived negative) attitudes towards people with disabilities. Attitudes towards people with disabilities have been studied in different ways. Speakman (1989) used an "Attitudes Towards Disabled People" questionnaire, but no further studies are known using this, or a similar, instrument. Jackson (1989) examined the levels of knowledge and experience that trainee social workers have about disability, as well as their beliefs and attitudes towards disability and rehabilitation. She found that these trainee social workers generally held positive attitudes towards people with disabilities and nearly all students expressed a belief in supernatural causes in conjunction with natural causes. Anthropologists and sociologists have also done descriptive studies. In a study of the Songye people in Zaire/Congo, Devlieger (1995) noted that there is not a general negative attitude towards people with disabilities and that deviations in the body can induce a higher, lower, or indifferent status. People with an indifferent status *("faulty people")* encounter an attitude of indifference towards their own situation. Instead, attention is directed at the problem underlying the fault. The person with a disability is not seen as abnormal but liminal, and she is seen as a person, like any other, with a right to development. Jackson & Mupedziswa (1988) carried out a study on beliefs and attitudes among people with disabilities in rural Zimbabwe. They concluded that the people with disabilities included in their study, do not hold a consistent worldview, and that they use rehabilitation services *"...either in conjunction with traditional services or to their exclusion regardless of beliefs of casualties"*. In their opinion 'negative' beliefs of causality did not exclude people with disabilities from community life.

Kisanji (1995) studied Tanzanian proverbs and presented examples in which people are urged to contribute to the welfare of the community according to their ability. He pointed out that in the history of Western countries, as in that of developing countries, examples of hiding, excluding, abandoning, and killing people with disabilities can be found. He concluded that *"Historically, therefore, attitudes towards disabled people have been a mixture of persecution as well as tolerance. However, the tolerance shown has been paternalistic"*. Research on the roles of people with disabilities in the community, and the community's attitudes, has been descriptive and is fragmented. Studies about a change in attitudes are rare and lack a proper research design (specifically a description before and after the intervention programme). An exception is a recent research study carried out by Thorburn (1998). She used a proper research design in a study of the attitudes towards childhood disabilities in Jamaica. The data *"provided a baseline for change in knowledge, attitudes and practice in community based service for children with disabilities"*. No follow-up research on these base-data is available at the moment.

Whereas studies describing and influencing attitudes in the 'general public' are reasonably common, studies influencing specific groups within the community are rare. An exception is probably the study on involving local craftsmen in the training of people with disabilities (Jagannathan, Ramamurthy, Jeyaraj, & Regina, 1993). The total absence of studies about influencing 'policymakers' in the community and at other levels is noteworthy as many project planners include influencing policymakers as a dominant aim of their projects.

4.2.1 Person with a disability

The first stakeholder to be discussed is the person with a disability. This stakeholder has a particular position in the process since she is the most direct beneficiary of the process. In fact, the entire rehabilitation process is based on the impairment or disability of the person and only exists because of the presence of this stakeholder (Bickenbach, Chatterji, Badley, & Üstün, 1999; WHO, 1980, 2000). It is known that this perception has been challenged by 'social model' advocates, who state that disability or handicap arises from grave defects in society and social attitudes, and that these should be the primary targets for action (Bickenbach et al., 1999; Finkelstein, 1998).

According to the manual, CBR programmes should be set up for *"...the rural and urban poor, concentrating on the major categories of disabilities or handicaps caused by locomotor, speech, hearing, seeing and mental disorders"* (Helander, Mendis, Nelson, & Goerdt, 1989). In practice, CBR projects are often set up for limited and selected groups of people with disabilities such as projects directed at specific groups of people with disabilities (e.g. people with mental retardation, people with locomotor disorders) or age groups (e.g. children, the elderly). Also, organisations can be identified that offer a specific type of assistance or type of rehabilitation (e.g. medical, vocational, educational). Organisations have their own backgrounds and missions and are often part of, or related to, Ministries or Non-Governmental Organisations with a specific interest in certain aspects of disabilities.

Selection of the people with disabilities to be included in a CBR project is apparently done according to criteria set by other stakeholders and not by the people with disabilities themselves. Thus it does not necessarily reflect the needs of people with disabilities. However, research studies or reports that look specifically at the needs of the people with disabilities in

CBR appear not to be available. In her article, Greenwood (1985) pleaded for a needs-generated approach, but she does not include references of studies that have used this approach. It is therefore not known whether people with disabilities look for financial assistance, medical care, schooling, or vocational training and what the priorities for different groups of people with disabilities may be. Research within CBR projects is heavily biased since people with disabilities will be tempted to ask for whatever they think the interviewer, as an extension of the service provider, has to offer. For example, if the interviewer is someone from social welfare they might ask for financial assistance, or if the interviewer is a medical person they might ask for medication or appliances.

The expressed needs of people with disabilities will depend on their perception of their position, their understanding of the disability, their ambitions, etc. Greenwood (1985) wrote: *"There is far too little research on group and individual meanings of disability"*. And in an article on health problems in rural communities in Zimbabwe, Mutambirwa (1989) stated that: *"In many communities of the developing world formal health services are introduced without first understanding how the people perceive their health needs, health problems and what they do about them"*.

Service providers (trainers, institutions) and people with disabilities differ in their opinions about the aims and methods of the rehabilitation process. This is painfully illustrated by Kassah (1998) when he describes a situation in Ghana where people with a disability did not want to participate in a CBR programme but would *"rather migrate to the cities to beg"*. There seems to be little research evaluating the differences between what service providers can offer and what consumers need. An exception is a study done by van der Hulst (1993) in which she discussed the difference in expectations between people with disabilities and rehabilitation workers involved in the CBR projects in Zimbabwe. She described it as a negotiation process in which both parties would try to realise their aims.

People with disabilities are, during the rehabilitation process, in direct contact with family trainers and volunteers, and indirectly, with rehabilitation workers at district, provincial, or national levels. Apart from this line of support (see figure 3.3, page 67) people with disabilities have formed organisations of their own (Disabled People Organisations, Independent Living Movements, advocacy movements etc.) to support each other and to express common needs. One of the founders of the National Council of Disabled People Zimbabwe (NCDPZ), Phiri, said: *"what we had in mind had nothing to do with service; it was an advocacy or pressure group"* (CBR-News, 1990). Service providers and disability movements both aim at improving the quality of live of people with disabilities, but they differ in their methods, means, and interests. These interests might be conflicting, but they can also be complementary to each other. Cornielje (1993) reported a CBR project in Alexandra town where, after a difficult start, the disability movement now works together successfully with the Alexandra Health Centre. The disability movement is now represented in different local committees and takes part in the CBR courses.

One of the main reasons for introducing CBR in developing countries was the high numbers of people with disabilities whose needs have not been met by rehabilitation services. This number is commonly assessed through disability surveys and prevalence studies. Prevalence studies generally present the numbers of people with disabilities more than their needs or resources (e.g. Davies, 1983; Finkenflügel, 1991b; Katzenellenbogen, Joubert, Rendall, Coetzee,

1995; Lundgren-Lindquist & Nordholm, 1993; McLaren, Gear, Irwig, & Smit, 1987; Ministry of Labour and Social Services Zimbabwe & UNICEF, 1982; National Statistical Office, 1987; Njini, Goerdt, Hanekom, & Lagerkvist, 1991; United Nations, 1990). It is surprising that so much attention is focused on prevalence studies. The outcome of these studies will invariably show high numbers of people with disabilities and will again confirm the limitations of the services available. In addition, it appears to be hardly possible to compare disability surveys and derive the needs of people with disabilities from such studies. The surveys do not only differ too much in terminology, but they also leave the basic question 'what is a disability' unanswered. This might seem obvious when talking about someone who lost a leg through a land-mine accident, but what about someone with a mild learning disorder who is able to support her/his family, someone with dyslexia living in a rural area, or the woman who is not able to have children. Instead of merely establishing prevalence, research should aim at identifying the needs of people with disabilities and the resources through which people with disabilities manage their lives in families and local communities.

4.2.2 The Family and the family trainer

The first caring environment experienced by a person with a disability is generally her own family. When including the family in the rehabilitation process, we first have to establish who is part of the family, what the expectations of the family are regarding the family member with a disability, and what type of support the family needs. According to research done by Singhi, Goyal, Pershad, et al. (1990), families in India are affected by having a child with a disability: They observed that *"Families with disabled children perceived greater financial stress, frequent disruption of family routine and leisure, poor social interaction, and ill effects on the physical and mental health as compared to families of control children"*.

Considering the importance attributed to the family, it is surprising that there is still little research about the involvement of the family in the rehabilitation process. O'Toole (1989) commented that intervention programmes *"...may become too highly child-focussed and overlook the wider needs of the family as a whole"*. Not all parents welcome a teaching role and will find practising with their child with a disability rewarding. He concluded that parental involvement programmes could only be successful if these *"...become an integral part of the mother's day rather than making unrealistic extra demands on an already overburdened mother"*. Mehretu & Mutambirwa (1992) supported the statement that mothers are already overloaded with duties. They measured 'time and energy costs of distance in rural life space of Zimbabwe' and found that 25% of the daily time and energy budgets for each household member was spent on activities such as fetching water, collecting firewood, and grazing livestock. These activities are mostly carried out by women who also have the responsibility for the nutritional and health status of the other members of the household. They concluded that *"...considering the role of wives (mothers) in rural settings in Africa, reduction of time cost of distance and energy cost of distance associated with routine domestic chores may be given the highest priority"*.

The main question appears to be whether or not the family is willing and able to train the family member with a disability. Families might have different, even unrealistic, expectations of rehabilitation. They might expect the rehabilitation workers to train and take care of the person with a disability, and they might not be aware that rehabilitation is often a long-term

process and improvements sometimes come very slowly. Information on all aspects of the disabilities and on how people with disabilities can develop themselves are essential for developing the motivation and realistic expectations of family members. In a research study about the CBR-projects in Zimbabwe, Finkenflügel et al. (1996) observed a relation between the perceived ability to teach the child with a disability functional skills and the expectations for the future of the child. Further research on the involvement of the families, i.e. how families can function as a caring and stimulating environment, is definitely needed.

4.2.3 Community Rehabilitation Worker / Local Supervisor

Community Rehabilitation Workers or Local Supervisors (later changed to Local Facilitator (Helander, 1999)) do their work on a voluntary basis. Projects might make use of already existing cadres such as Village Health Workers or Community Workers and by asking them to devote part of their time to CBR alongside their other community activities. Some projects work with an 'own' group of volunteers and will sometimes provide incentives such as soap, food, or little presents or they will give awards for the 'volunteer of the year' to express appreciation and provide motivation. Helander (1993) explained that voluntarism is appreciated very differently in countries in Asia, South America, and West Africa. In some cultures being a volunteer contributes to position and status whereas in other cultures people are encouraged 'not-to-work-for-nothing'. In some countries, community initiatives might even be perceived as subversive action.

Not much is known about the motivation of volunteers in CBR. Are they involved because they want to do something with and for a community member with a disability? Are they looking for job opportunities or for some kind of financial gain? Another relevant question is whether or not we expect the community to support the Local Supervisor. Will the community compensate her for spending her time in the programme and thus giving up her ability to work on the fields?

Information on the position of the Local Supervisor is also scarce. Does she represent the community or the rehabilitation programme? In South Africa, the SACLA project worked with Community Rehabilitation Workers who were chosen by the 'community of handicapped people' (Loveday, 1990). These rehabilitation workers were trained in an intensive four-week course and employed by SACLA. In CBR projects in Zimbabwe it appeared not to be too difficult to find volunteers to do a house-to-house survey or work on a short-term assignment. It was more difficult and challenging was to keep these volunteers involved and motivated in the follow up stages of the projects (Rottier, Broer, Vermeer, & Finkenflügel, 1993).

Local Supervisors need training in order to be educated in the various aspects of the rehabilitation process. Training appears to be a good reinforcement for keeping volunteers involved. Training can be organised using the WHO-manual (Helander, Mendis, & Nelson, 1983; Helander et al., 1989) but always needs to be tailored specifically to the situations the volunteers will come across during their work. No studies are carried out regarding the impact of training, i.e. regarding how and to what extent will the interventions of the Local Supervisors be changed as a result of the knowledge and skills gained in the training.

4.3 Stakeholders at the district, provincial, and national level

The stakeholders described in this paragraph are people involved at the district, provincial, and national level (figure 3.3). Again, it is possible to identify many more (latent) stakeholders. At these levels, people generally function within organisations and thus answer to the goals of an organisation as well as their own private goals. Organisations endeavour it can be noted that they have to achieve 'public' goals but there are discrepancies between goals like 'health for all by the year 2000' or 'integration of people with disabilities' and the 'own' goals of an organisation or leading persons in those organisations. In her article with the controversial title "Reorienting health care in Africa - can the élite believe in equity?", Einterz (1996) illustrated this by saying that the *"...reorientation of funds requires those in power to slash and scatter their power base"*. The question then is: 'Do we really expect people in influential positions to give up privileges or redesign a system that will make them replaceable, superfluous or less important?'. Organisations might also adopt aims and objectives that have not yet been accepted by the other stakeholders in the rehabilitation process or are not seen as a priority. One example is the policy on gender issues in health; some organisations make it an explicit objective to make health care available to women. Organisations involved in rehabilitation can be found that choose only to assist co-operatives for women or to pay school fees for girls with disabilities only. This preferential policy is difficult to explain to communities, community leaders, and rehabilitation workers. It simply comes down to the fact that organisations have their own specific aims. Organisations of professionals will primarily look at the interests of the professionals they represent, and project or donor organisations will have a desire to survive and thus will choose projects that strengthens themselves. Choices might also be fuelled by a desire to get good publicity and to be attractive for employees, donors, etc. There is always a chance that these types of aims may become a more important issue than providing services that will be beneficial to people with disabilities. Therefore, organisations should be approached as an entity with its own goals. In addition, one should be on the alert if an organisation's goals aim towards empowerment of people with disabilities and strive for a high level of involvement in decision making for all *stakeholders* in the rehabilitation process. Often these organisations get nervous when people with disabilities want a real say in the organisation itself and want to influence goal setting, distribution of resources, and staff employment.

The main stakeholders within the professional rehabilitation services will be discussed hereafter.

4.3.1 Rehabilitation Assistant / Intermediate Level Supervisor

The Rehabilitation Assistant or Intermediate Level Supervisor is, in most programmes, a formally trained professional. She could be a nurse, a social worker, or a teacher with a few months additional training, or she could be a rehabilitation worker with a one to two year training in rehabilitation and different professional backgrounds (e.g. in medical rehabilitation, vocational rehabilitation, special education, or social work). In practice, it will be the aims and objectives of the programme, rather than the needs of people with disabilities, that determine what type of education is required for this position.

In Zimbabwe the Ministry of Health started a Rehabilitation Technicians Training School. Initially the Rehabilitation Technicians (formerly called: Rehabilitation Assistants) were seen as an affordable way to provide rehabilitation for people with disabilities. It was presented as a short-term solution because, in the long run, it was foreseen that enough physiotherapists and occupational therapists could be trained to attend people with disabilities in the future. However, these Rehabilitation Technicians have acquired a specific role in, and are now an essential part of, the practice of decentralisation of rehabilitation services in Zimbabwe (Finkenflügel, 1991a; Hanekom, 1983; Mpala, 1998). McLaren (1986) proposed a four-tiered rehabilitation delivery system for rural health services in KwaZulu, South Africa. At the rural level, paraprofessional workers (rehabilitation therapists) recruited from their own area work under supervision of professional therapists. Dolan, Concha, & Nyathi (1995) conducted a study also in South Africa on the training of Community Rehabilitation Workers who, after a two-year training, became entirely community-based and only used the district hospital as a referral centre and resource base. These Community Rehabilitation Workers worked directly with people with disabilities and thus appear to have combined the Local Supervisor and Intermediate Level Supervisor into one person. Cornielje & Ferrinho (1995) and Deetlefs (1995) described the training and practical experiences of Community Rehabilitation Facilitators. During this two-year training programme rehabilitation was approached as part of community development. Training focused on the enhancement of knowledge and skills in community development, and thus contrasted with medically-oriented training. In Malawi, Malawi Against Polio (MAP) trained MAP-assistants for their outreach rehabilitation services (Chipofya, 1993). Overall, there are a lot of differences in the type of training (duration, contents, and teaching methods), but there are also in the positions occupied by these rehabilitation workers. They might be perceived as 'assistants' of the established rehabilitation professionals, or they might be seen as a full-grown that is supervised but works independently with Local Supervisors and people with disabilities.

4.3.2 Trainer

According to the WHO-CBR model trainers are professionals in referral centres at district/provincial levels working in the fields of education, health, or vocational training. These professionals train and supervise Intermediate Level Supervisors and additionally will provide diagnostic and rehabilitation services for people with disabilities referred to them by Intermediate Level Supervisors. These professionals (nurses, physiotherapists, occupational therapists, social workers, teachers, vocational trainers) usually run CBR projects. Some projects have even been run by the people with disabilities themselves (the most famous example is probably project Projimo (Hesperian-Foundation, 1983; Werner, 1990)), but in these cases they are not likely to use the term CBR for their projects. In practice, 'community' participation in management of CBR projects is minimal and is usually in the hands of (non-disabled) professionals.

Mendis, a physiotherapist by training and involved in CBR from the start, comments on the role of the physiotherapist in primary health care in developing countries. She argues that there is a *"...need to reconceptualise our role in rehabilitation along the lines of the new approaches so that we are capable of guiding primary health workers, the community, the family and the disabled in the*

total rehabilitation process" (Mendis, 1982). McAllister (1989), an Irish physiotherapist, wrote about her personal experience in Zimbabwe. She appeared to be impressed by what is, and can be, achieved although she pointed out that expatriate therapists encounter many frustrations and limitations in their work as it involves many administrative duties. Therapists who become trainers in CBR projects are often forced to change roles. Occupational therapists and physiotherapists are trained to assess the limitations in function of the person with a disability, to set treatment objectives, and to provide direct, hands-on therapy, often with the use of equipment. In CBR, trainers only work indirectly with people with disabilities. Their task is to train the intermediate professionals and to organise training and feedback sessions for them. Trainers should be able to transform often complex treatment practices into functional skills that Intermediate Level Supervisors can understand, use, and pass to Local Supervisors or, depending on the type of CBR project, the family trainer. In the manual (Helander, 1983), and also later by O'Toole (1987), this has been called the 'de-mystification' of rehabilitation. Although many of the skills to be learned by Intermediate Level Supervisors and Local Supervisors may be new, it is also important to realise that people have always dealt with people with disabilities and have some understanding of (ab)normal development, the problems that people with disabilities encounter, and the ways in which people have solved problems so far. A well-documented example is the way mothers in Jamaica handle their children. They traditionally use a set of handling routines to test and train their children and adapt these routines if the child is not responding in the expected manner. (Hopkins & Westra, 1988; van der Putten, 1999; van der Putten, Finkenflügel, & Thorburn, 2001). This example shows that already existing knowledge and skills can be used as a basis for learning new or additional skills. Elaborating on Mendis´ quote given above, it can be said that trainers build on existing knowledge, break down complex practice to functional skills, have a good understanding of how, when, and where the skills are being used, use different training methods, and organise feed-back and follow-up sessions. To conclude, it is important to point out that it is not only medically trained professionals that get involved in CBR. For exmaple, the School of Social Work in Zimbabwe offered a one-year Certificate Course in Rehabilitation (Zhoya, 1986).

4.3.3 Specialists

'Specialists' include highly qualified professional rehabilitation workers and medical doctors in training institutes and treatment centres at the national level. Like the therapists at the provincial level, they are available for people with complex disabilities and the stakeholders working directly and indirectly with them. In figure 3.3 (page 67) the distance between specialists and the community and living space of the person with a disability is large. Therefore, the amount of time spent by a specialist on an intervention (advice, prescription of drugs, operation, intensive training etc.) will be limited. Aftercare, (re-)socialising, etc. will be left to trainers and Intermediate Level Supervisors, Local Supervisors, and family. As such, the role of specialists in CBR is limited.

4.4 Anticipating the influence of stakeholders

Having identified, and discussed, the different stakeholders involved in CBR, the next step in this stakeholders analysis is to anticipate the influence these stakeholders will have in the CBR process. The word 'influence' refers to the 'position' in the process, the 'competence', and the 'decision making capability' of the stakeholder. These aspects underlie the concept of 'empowerment', which was defined before as *"to give the power to act"*. The 'position' of each stakeholder in the process has already been described extensively. 'Competence' will be used here to describe the level of authority, ability, skill, knowledge, and attitude of the different stakeholders. The influence of a stakeholder is best seen in the decision-making processes. The main question here is to what extent will the different stakeholders be able to adapt or change their role in the process. Are the stakeholders (i.e. the Local Supervisors and Intermediate Level Supervisors) perceived as 'extended arms' of the trainers and thus merely play an instrumental role in CBR? Or do all stakeholders operate more or less autonomously within their area of competence and make all necessary decisions? Are they able to change objectives, target groups, training contents, etc. by themselves?
First the anticipated competency-level of the stakeholders will be discussed, followed by a discussion of their subsequently the 'decision making capability'. This will provide a framework to be able to assess the efficacy of stakeholders in CBR. As such, it also functions as a normative framework. This framework will also benefit the development of strategies to obtain effective support for CBR (defined as step 3 in the stakeholders analysis).

4.4.1 Competency-levels of stakeholders

An overview of the different stakeholders involved in CBR has been constructed on the basis of different editions of the manual (Helander et al., 1980, 1983; Helander et al., 1989), adjoining documentation (Helander, 1984; Mendis, 1982; Mendis & Nelson, 1983), and articles focussing on specific groups of stakeholders (Dolan et al., 1995; Finkenflügel, 1991a; Hartung, Kelly, & Okamoto, 1989). This information is summarised in table 4.1 (page 84). The table will function as a reference in the further analysis of, and research in, CBR, and, as such, it is part of theory building in CBR. It can also be used as a normative framework to compare actual positions and competencies with the theoretical ones presented in the table which might reveal the need for additional training, support, etc. However, the table cannot be used as a blueprint for involving stakeholders in a specific project. In fact, each CBR project will have to define the competencies of stakeholders on the basis of the specific, and sometimes unique, objectives of the project and the local circumstances. For example, in some Muslim communities, women might be restricted from visiting the homes of others, and therefore would not be able to fulfil the roles of Local Supervisor and Intermediate Level Supervisor in the same way as, for example, women in Jamaica or Zimbabwe who are used to being out of the home for household duties, farming, etc. and can thus visit other homes easily.

4.4.2 Decision-making capability of stakeholders

Descriptions of the competency-levels of the stakeholders should be combined with an analysis of the 'decision-making capability' of these stakeholders in CBR. In projects where the

stakeholders function as 'extended arms', a management model with a strong 'chain of commands' will be found whereas a model based on a 'chain of support' will be suitable in situations where the stakeholders operate autonomously. These two models can also be referred to as 'top-down' and 'bottom-up' approaches, respectively. Also, countries will differ in their socio-economic circumstances, cultural backgrounds, political systems, etc. and these differences will be reflected in their decision-making processes. CBR is, like other development programmes, presented as a bottom-up approach (Helander 1993) with a strong involvement of people at the community level. If, and how, this approach conflicts with traditional and modern politics in some countries is not documented in the literature about CBR. Discussing decision-making in CBR also implies discussing the ownership of the project and thus probes the issue of empowerment of the different stakeholders. It can be concluded from what has been said before that CBR projects are very owned by organisations (government, NGO) and that 'collective' programmes like Project Projimo (Hesperian-Foundation, 1983; Werner, 1991) are still exceptions to the rule. The 'owners' of CBR projects usually include 'empowerment' as one of the objectives of the project. However, this objective addresses only one group of stakeholders: the people with disabilities.

A few comments regarding the availability of information to stakeholders in CBR should be made in this section. Stakeholders need information upon which they can base their decisions to adapt or change the intervention or the process. Information collected by the different stakeholders for monitoring and evaluation purposes often serve the programme owners only. To value and increase the decision-making capability of the stakeholders, it is necessary to include information that is useful for the stakeholders themselves, for the stakeholders they support, and for the stakeholders they have to account to. Examples of decision-making by the different stakeholders, and their related information needs, are provided in table 4.1 (page 84).

4.5 Discussion

This review of the different stakeholders involved in CBR illustrates that the rehabilitation process can be described as a complex system of interactions between stakeholders and within groups of stakeholders. Research on the competency-levels and influence of each stakeholder is still in its early stages and the available documentation is fragmented. In order to set up effective programmes and to assess how and why CBR-projects do (or do not) work in the expected way, different stakeholders should be approached as the main focus of, and participants in, the study. This requires a theoretical cadre in which the prospected competence and efficacy of the different stakeholders are directly related to the objectives of the project and in which the interventions by the stakeholders have been made explicit.

A stakeholder analysis, as used in this chapter, is a promising method to explore and analyse the working processes in CBR. It not only provides insight into the roles of the different people involved and makes these accessible for assessment and research, but it also reveals opportunities to improve the process. There is, however, a risk of 'constructing reality'. CBR projects might be more diffuse than can one would assume based on the discussion in chapter 3 and the stakeholder analysis in this chapter (e.g. in situations where people involved in CBR

Table 4.1 Competency-levels, decision-making capabilities, and information needs of the stakeholders

	Competency-level	Decision-making (examples)	Information needs
Person with a disability	– Assess of own situation, expectations, ambitions and perspectives of her/his own life and set goals for the rehabilitation process – Select a trainer – Negotiate with trainer on goals to be reached and assistance required	– Perceive her own role in different settings – Choose training (type, frequency, efforts), the use of aids and appliances, and who can assist to realise ambitions	– The potential to fulfil her own perceived roles as a family member, a pupil, a businessman, etc. – The effectiveness of training – The usability and availability of aids and appliances – The existence of support and advocacy groups
Family, family trainer	– Support the person with a disability, analyse of the situation, and set goals (i.e. with children or with people with a mental handicap or illness) – Train the person with a disability	– Perceive role of the person with a disability and the type, frequency and duration of training in case the person with a disability cannot speak for her/himself – Determine contents, methods and intensity of training	– The current abilities of the person with a disability in relation to desired abilities and individual capacity (incl. the use of aids and appliances) – Specificity (right type of training), effectiveness (are expected results reached), and efficiency (number of people with disabilities trained related to time spent with them) of training methods
Community rehabilitation worker (CRW) / Local Supervisor (LS)	– Perform (functional) assessment of the person with a disability covering ADL and relate this to the goals set by person with a disability and draw up a plan for training – Train the person with a disability and instruct the family member(s) – Identify obstacles in the community that prevent the person with a disability from reaching her goals and from participating in community activities – Mobilise community (promote awareness, acceptance, accessibility, attitudes, etc.)	– Determine number of family trainers to be trained – Determine methods used to train families / family trainers – Determine contents, frequency and duration of training – Suggest community members and organisations to be involved	– The current abilities of the (referred) person with a disability in relation to desired abilities and capacities – Number of people with disabilities trained by the family / family trainer, and efficiency of training – Effectiveness of training and perceived competence of family / family trainer – Involvement of community in training and changes in physical and social structures to make these accessible for people with disabilities

	Competency-level	Decision-making (examples)	Information needs
Intermediate local supervisor (ILS)	– Train CRWs/LSs – Assess, treat, and instruct of people with disabilities referred to a rural or district health centre – Support community rehabilitation workers in mobilising communities – Oversee daily running of rehabilitation programme in the district (operational)	– Determine number of CRWs trained – Determine contents, frequency, and duration of CRW training – Provide support for CRWs regarding training family trainers and involving community members – Determine use and distribution of resources	– Effectiveness of training of CRWs, number of CRWs involved, workload of CRWs, perceived competence of CRWs – The abilities of the (referred) person with a disability in relation to desired abilities and capacity – Effectiveness of the CRWs in mobilising communities – The availability of resources (manpower and funds) in relation to the objectives of the programme and its efficiency and effectiveness
Trainer	– Train LSs/RAs – Assess, treat, and instruct of people with disabilities referred to a provincial, national, or specialised health centre. – Initiate and facilitate rehabilitation projects in districts (tactical)	– Determine number of ILSs trained – Determine contents, frequency, and duration of ILS training – Provide support for ILSs in training CRWs – Determine use and distribution of resources for existing and new programmes	– Effectiveness of training of ILSs, number of ILSs involved, workload of ILSs, perceived competence of ILSs – The abilities of the (referred) person with a disability in relation to desired abilities and capacity – The availability of resources (manpower and funds) in relation to the initiation of a rehabilitation programme, the objectives of the programme, and its efficiency and effectiveness
Specialist Project planner, implementer	– Provide professional education of therapists – Assess, treat, and instruct of people with disabilities referred to a specialised centre – Take overall responsibility for rehabilitation projects, including organising support for the project and manpower planning.	– Determine number of trainers trained – Determine contents, frequency, and duration of trainer training – Provide support for trainers in training ILSs – Acquisition and distribution of resources	– Effectiveness of training of trainers, number of trainers involved, workload of trainers, perceived competence of trainers – The abilities of the (referred) person with a disability in relation to desired abilities and capacities – The availability of resources in relation to the mission statement, the number of people with disabilities, the expectations of the people with disabilities, and the objectives to be reached at the different levels – The efficiency and effectiveness of the rehabilitation programme in relation to other initiatives working with a similar mission statement and objectives

have different and inconsistent roles, the project lacks a clear structure, the competence level of the stakeholders do not match the decision-making capabilities, or the information flow is non-existent or only serves a specific group of stakeholders). It is also important to realise that the diversity within a group of stakeholders can be vast. This has already been discussed in the context of people with disabilities and the community, but will it definitely apply to the other stakeholders as well.

A group of stakeholders that have not been discussed are the local authorities who have their power base in the community. They often have to share this power with traditional leaders or political parties. Thus, stressing and developing the competence of different stakeholders in combination with empowering people with disabilities and their families can easily be seen as a challenge to existing power structures.

A group of stakeholders in CBR includes a wide diversity of people with a wide range of interests. Some groups have organised themselves in support or pressure groups, e.g. Disabled People Organisations, parents organisations, and alliances of professionals. These different groups will advocate their interests in policy making, division of funds, etc.

Although CBR has initially been presented as a humanitarian programme (and thus suggests that disability and rehabilitation are not political issues) it is important to realise that stakeholders have their own interests in the project. This personal interest might fully serve the project (for example a Rehabilitation Technician who wants to increase her competence and enters additional training), but it might also detract from the projects' objectives.

Regarding the information needs of the different stakeholders it is stressed here that information collection should be consistent with, and supportive of, the decision-making capabilities of the stakeholders. Monitoring and evaluation instruments generally calculate the number of people involved in the project, the number of appliances given, the number of children with disabilities going to a mainstream school, etc. Some instruments have collected an impressive amount of data (Jönsson, 1994; Vanneste, 1996), but it is not clear if and how the different stakeholders can actually use the data to assess and improve their own effectiveness and that of the stakeholders they support.

At the conclusion of this analysis, the role of stakeholders in CBR has not been explicitly linked to the specific objectives of CBR projects. So far, in the discussion far the roles of stakeholders have been derived from a general concept and understanding of CBR. With regards to the reservations encountered in the division of CBR as concept, similar reservations exist in the discussion of the role of stakeholders in the rehabilitation process. In order to overcome these reservations it is important to link the project objectives directly to the perceived roles of the stakeholders involved.

Empowerment of stakeholders in CBR projects in Southern Africa

5

Abstract

This study explores and analyses the characteristics of the different stakeholders and their roles in influencing and achieving the objectives of CBR projects. Documentation of CBR projects in Southern Africa has been reviewed. Ten projects out of the more than 30 projects identified have been included in the study. For these ten CBR projects, the stakeholders have been identified, and the objectives of the project have been analysed. Subsequently, the objectives of the project have been related to the interventions made by the different stakeholders involved. In these studies, the role of the Intermediate local supervisor or Rehabilitation Assistant is emphasised. In the projects studied, this cadre played a dominant role in CBR as the most decentralised and community-oriented rehabilitation worker. In fact, CBR, appears to rely completely on the involvement of this type of rehabilitation worker. It is concluded that, with such a strong emphasis on this cadre, and its inclusion in a professional rehabilitation system, the influence of other stakeholders (i.e. the non-professional stakeholders) stays unfocused.

5.1 Introduction

In chapter 4, the relevant stakeholders in Community-based rehabilitation projects have been described extensively in terms of their role and position in the process, their contributions to the project objectives, and their ability to influence the CBR. Research question three was addressed using a normative description of the competency-levels, decision-making capacities, and information needs of these stakeholders. In this chapter the literatures study assessing the roles and positions of stakeholders in 'real life' CBR projects is discussed in order to elaborate on the previous chapter and advance to research question four. To reduce error due to the cultural diversity and socio-economic variables, the study had to be limited to CBR projects conducted within a specific region. The literature review (chapter 2) revealed that, with 35 articles, Sub-Saharan Africa was relatively well documented. Since 29 of these articles concern the ten countries in the Southern African region (Angola, Botswana, Lesotho, Malawi, Mozambique, Namibia, South Africa, Swaziland, Zambia, Zimbabwe), a further reduction of the study area could be made.

5.2 Identifying CBR projects in Southern Africa

The basis of this study was formed by the 29 CBR studies conducted in the Southern African that were identified and discussed in the literature review (chapter 2). In order to study the interests, and influence of the stakeholders involved in these CBR projects more comprehensively, these studies were complemented with 'grey literature' (progress and evaluation reports, brochures, electronic resources, annual reports, newsletters, theses, chapters in books, and articles published in journals which did not meet the inclusion criteria used in the literature review). Limiting the study to countries in the Southern African region will aid the interpretation of the findings. However, it also limits the ability to generalise results with those of CBR projects in other regions. It is also important to note that the selected region is still very diverse in many

aspects such as population groups, languages, income, health status, cultural and political backgrounds. For practical reasons, this study relies on literature written in English and therefore does not include studies written in other languages (e.g. Portuguese, Afrikaans, Shona, Setswana, Bantu, Ndebele).

In this study, a literature search using MEDLINE[1], SOURCE[2], and bibliographies made available by organisations[3] or researchers[4] was carried out. This was combined with evaluation reports, articles in non-scientific journals, (electronic) newsletters (e.g. 'CBR news'/'Disability Dialogue', 'Disability World'. 'ICACBR update', 'HealthWrights'), and information available on the Internet[5]. Studies about conditions not commonly accepted as part of the domain of Community-based rehabilitation (for example, people with epilepsy, people who are malnourished, or people who are considered socially deviant (e.g. because of infertility, ugliness, illegitimate birth)), were not included in this study.

A total of 97 documents, covering approximately 35 projects were found. Six studies could not be linked to a specific CBR project. (e.g. Bortz, Jardine, & Tsuhle, 1996; Brodin & Molosiwa, 2000; Coetzee & Kemp, 1982; McConkey & Mphole, 2000; S. Miles, 1996; Whyte & Ingstad, 1998). Also, some projects appeared to be known under different names or as part of another project, and these were not necessarily a CBR project. It is assumed that the number of projects identified in this study presents an under-reporting of the total CBR projects since reports on rehabilitation projects are not distributed widely and are not easily available to people outside the project, organisation, or country. This fact was illustrated by experiences at a conference on CBR in Southern Africa in Harare in 1998 (Cornielje, Jelsma, & Moyo, 1999). At this conference, all participants presented a brief review of the CBR projects in their country. Not only were these projects often unknown to people in neighbouring countries they were sometimes even unknown to colleagues in the country itself. Vanneste (2000) estimated the number of projects in Sub-Saharan Africa (excluding South Africa) to range from 200 to 220 (or approximately six projects per country). Although the identified projects do not present a full picture of CBR projects in Southern Africa, the number of projects that could be identified is assumed to be sufficient for the current study. The level of documentation per project differed greatly between projects. Some projects were covered relatively well and could be located by name or region, but some projects were only found based on references made to it in policy documents, annual reports (e.g. APSO, 1999) or reports about other projects. For example, Serpell & Nabuzoka (1989) referred to *"three or four"* other CBR projects and Kathleli, Mariga, Phachaka & Stubbs (1995) mentioned three projects in Lesotho. The projects identified and the documentation used are presented in table 5.1.

The search comprised a time period of two decades. It is unknown how many, and what type, of projects exist at any given time. Little is known about the 'life-cycle' of CBR projects, and concerns about their sustainability have been expressed (Ager, 1990). Rißе (1991), for example, mentioned in her study that the 'Zimcare home based programme' (Mariga & McConkey, 1987), one of the projects included in this study, had stopped due to lack of funding. MacLachlan (1993) argued that *"an increasing number of 'third world' health development projects are proving to be unsustainable once foreign aid has been withdrawn"*.

The terms 'CBR-programme' and 'CBR-project' are both commonly used in the documentation studied. Although these are often used interchangeably, it appears that 'projects' generally refer

Table 5.1 Overview of CBR projects and available documentation

CBR projects	**Research studies** (see chapter 2)	**Reports and other documentation**
Angola		
1. Center for community-oriented rehabilitation (Medico International)	—	Tietze (1999)
2. Social Integration project with disabled people (Handicap International)	—	Harknett (2000)
Botswana		
3. Botswana Red Cross CBR programme	Lundgren-Lindquist & Nordholm (1993)	Botswana Red Cross (1988)
Kweneng (project South) and Tutume (project North)	Lundgren-Lindquist & Nordholm (1996)	Gabanameko (1989), Waaler (1991)
	Nordholm & Lundgren-Lindquist (1999)	Ingstad (1995, 1997, 1999b, 2001)
	Ingstad (1990)	
4. Ministry of Health (SSU) CBR programme	Kibria (1989)	Sebina & Kgosidintsi (1981)
		WHO (1982, 2003)
		Ingstad (1995, 1997, 1999b, 2001)
5. Mogoditshane Rehabilitation Centre CBR-programme	Popovich (2001)	
Lesotho		
6. "three CBR programmes"	—	Khatleli et al. (1995)
7. Scott CBR project	—	S. Miles (1995)
		Arnold (1995)
Malawi		
8. Malawi Against Polio (MAP)	—	Hyde (1992), Chipofya (1993)
		van Maanen (1999)
		Davies & Finkenflügel (1995)
9. MACOHA	—	van Maanen (1999)
Mozambique		
10 Ministry of Social Welfare (MIMUCAS): pilot CBR projects:	—	WHO (2003), Heinonen (2000)
ABC programme Maputo		S. Miles & Medi (1994)
Ministry for Social Action: Community based support programme		Medi (1997)

CBR projects		Research studies (see chapter 2)	Reports and other documentation
Namibia			
11 National CBR pilot (Tsandi division) Ministry of Land Resettlement and Rehabilitation (MLRR)		—	WHO (2003), United Nations (2002)
South Africa			
12 *Western Cape:*	- SACLA Health Project	—	Loveday (1990, 1993)
13 Alexandra Health Centre: Institute of Urban Primary Health Care (IUPHC):		Ferrinho et al. (1993)	Cornielje, Ferrinho, & Fernandes (1994) Cornielje & Ferrinho (1999)
Gauteng:	- Alexandra CBR programme	—	Cornielje & Ferrinho (1993, 1995) Deetlefs (1995), Cornielje (1993)
	- Winterveldt / Oukasie: Odi district	Taukobong (1999)	—
Mpumalanga:	- Botshabelo	—	—
North West province:	- Ditsobotla	—	—
14 Wits-Tinswalo Community Rehabilitation Worker Training Programme (CRWTP):			
Free State:	- Bushbuckbridge	Lorenzo (1994)	—
Mpumalanga:	- Mhala / Gazankulu	Dolan et al. (1995)	—
Northern Province		Petrick et al. (2001)	—
15 *Kwa Zulu Natal*	- Maputaland / Manguzi	—	McLaren (1981, 1986)
	- Thuhukani CBR programme Emtshezi / Okhahalmba (1989)	—	Fenenga (1997) McLaren, Phillpott, & Mdunyelwa (2000)
	- Amawoti	—	S. Miles (1996), Philpott (1995)
Swaziland			
16 National CBR Ministry of Health		—	WHO (2003), S. Miles (1995) Save the Children UK (2000) Mutangira & Nkosi (1993)

CBR projects	Research studies (see chapter 2)	Reports and other documentation
Zambia		
17 Zambia National Campaign to reach Disabled Children (ZNCRDC)	Serpell (1986)	Serpell & Nabuzoka (1989)
- Katete district (Vulamkoko ward) / Zambezi districts	—	Serpell & Nabuzoka (1985) Nabuzoka (1993)
- CBR project: Kasama district	—	Vermeulen (1989), Nabuzoka (1989)
18 CBR project in Mense	—	Nabuzoka (1988)
19 Ministry of Health / Chipata district CBR Programme	—	Payne & Simwanza (1998), WHO (2003)
Zimbabwe		
20 Zimcare	Mariga & McConkey (1987)	McConkey & Templer (1986) McConkey (1988), Mariga (1988)
21 Ministry of Health CBR programme pilot projects in eight districts, later expanding to 31 districts.	McAllister (1986) Finkenflügel (1991a, 1991b) Rottier et al. (1993) Finkenflügel et al. (1996)	Tiroler & Rubenson (1985), CIIR (1990) Ministry of Health Zimbabwe (1990a) Njini et al. (1991) van der Hulst (1993, 1994) Mpala (1998) Chidyausiku et al. (1998), WHO (2003)
22 Zimbabwe Red Cross CBR programme: Mutoko district (1982), Gutu district (1986), Beitbridge (1990)	Lagerkvist (1992)	Zimbabwe Red Cross Society (1981, 1982, 1987), Rißе (1991) Rumano (1988), Ingstad (2001)
23 Ministry of Health Zimuto (Masvingo province) (1987)	—	Munandi (1988) Chidyausiku et al. (1998)
24 TOSE Respite Care Home	—	APSO (1999)
25 Rural membership development programme: National Council of Disabled People of Zimbabwe (NCDPZ)	—	NCDPZ (undated), CBR-News (1990) Csapo (1986), Coleridge(1993)
26 Children's rehabilitation unit: Community based parents' groups (CBPGs)	Jelsma et al. (1995)	Hanekom (1988b) Hanekom-Jelsma & Cortus-Meldrum (1993)

to the practical implementation of CBR and 'programme' is mainly used at the planning and policy levels. As such, a 'CBR programme' can include more than one project (e.g. the Botswana Red Cross CBR programme comprised projects in Kweneng and Tutume (Botswana Red Cross, 1988)). In this chapter, both of the terms 'projects' and 'programmes' are included and all are referred to as CBR projects.

The CBR projects differed greatly with regards to the number of people assisted and the area covered. Some projects were run by one or two people that had been assigned to the project by, for example, the hospital, health centre, school, or social welfare department, who besides their regular obligations, worked on the project for one or two days per week. Other projects were staffed by a team of rehabilitation workers, clerks, drivers and other personnel working full-time. The amount of time and staff devoted to the project will definitely have implications for the roles the different stakeholders are expected to fulfil. In this study, autonomous CBR projects (with their own organisational structure) as well as CBR projects attached to other (institutional) projects are included (e.g. Jelsma et al., 1995).

Whereas projects may have faded, others were incorporated into other CBR projects (e.g. the CBR projects run by the Zimbabwe Red Cross (Zimbabwe Red Cross Society, 1982, 1987) were later handed over to the Ministry of Health and incorporated into their CBR projects), or they were incorporated into more general development programmes and thus became invisible as a separate or specific CBR project.

Some CBR projects aimed explicitly at the expansion of the project and used an approach whereby expansion was dependent upon the (increasing) availability of manpower, transport, and other resources. An example of this approach was found in the Ministry of Health projects in Zimbabwe. The Ministry began its nationwide CBR initiative by setting up eight pilot projects. With the experience gained from these early projects, and by training more Rehabilitation Technicians, the project had expanded to 31 of the 55 districts by 1997 (Chidyausiku, Munandi, Marasha, et al., 1998). Some of these projects already cover the whole district, but most are currently covering only part of it and are gradually expected to expand to cover the whole district.

5.3 Stakeholders identified in the CBR projects

In the articles reviewed many names were used to describe the stakeholders involved in CBR projects. Already 27 different names were found in the reports of CBR projects in the Southern African region and, without a doubt, the list would increase if CBR projects from other regions (i.e. Asia) were included. However, inmost cases these names could be well matched with the six principal stakeholders identified and discussed in chapter 4. In table 5.2 an overview of the various names used for CBR workers is given at four levels. It is important to note that a range of labels such as 'disabled people', 'people with disablements', 'clients' and, of course, 'people with disabilities' was used. To be consistent, the term 'people with disabilities' was used in both the text and the tables, even if a different name was used in the documentation studied. As a result, the reasons that authors might have had to use a specific terminology were ignored. For other stakeholders, there was no strict preference for use a given set of names.

Table 5.2 Names used for CBR workers

Stakeholder	Name used & references
First level CBR workers	– Local Facilitators (Chidyausiku et al., 1998)
Community level	– Village Health workers (Zimbabwe Red Cross Society, 1987)
CRW / LS	– Auxiliary workers (McLaren, 1981)
	– Village Community Workers (Chidyausiku et al., 1998)
	– Red Cross Volunteers (Nordholm & Lundgren-Lindquist, 1999)
	– Family Welfare Educators (Ingstad, 1997; Sebina & Kgosidintsi, 1981)
	– Health Surveillance Assistants (HSAs) (Malawi Against Polio, 1998)
	– Community-based (contraceptive) distributors (Zimbabwe Red Cross Society, 1987)
	– Health Assistant (Nabuzoka, 1988)
	– Development officer (Nabuzoka, 1988)
Second level CBR workers	– Social Welfare Officer (SWO) for the Handicapped (Sebina & Kgosidintsi, 1981) (Ingstad, 1997, 2001)
County / District level	– Red Cross Field Officers (Ingstad, 1997) (Zimbabwe Red Cross Society, 1981)
ILS / RA	– Community-based rehabilitation Worker (CBRW) (Bortz et al., 1996)
	– Community Rehabilitation Facilitator (CRF) (Cornielje & Ferrinho, 1993; Dolan et al., 1995)
	– Community Speech and Hearing worker (CSHW) (Bortz et al., 1996) *
	– MAP physiotherapy assistant (Chipofya, 1993)
	– Rehabilitation Assistant (Csapo, 1986; Dolan et al., 1995; Finkenflügel, 1991a; McLaren, 1986)
	– Rehabilitation therapist (McLaren, 1986)
Third level CBR workers	– Occupational therapist
Provincial level	– Physiotherapist
Trainer	– Senior Welfare Officers (Ingstad, 1997)
	– Regional Field coordinator (Red Cross Z.)
	– Speech therapist (Bortz et al., 1996)
Fourth level CBR workers	– Commissioner (Ingstad, 1997)
National level	– Orthopaedic Surgeon (Hyde, 1992)
Specialists	– Control therapy post (McLaren, 1986)
	– Flying doctor service (Nabuzoka, 1988)

* The Community Speech and Hearing Worker (CSHW) receives a training similar to the CBRWs but their training is specialized on communication impairments. Bortz et al. place the CSHW between the CBRW and the speech therapist. The initial identification is done by the CBRW who refers to the CSHW (Bortz et al., 1996).

People who are responsible for an exclusive task in CBR and who are specifically educated in CBR or other forms of rehabilitation were included in the four levels of CBR workers in addition to stakeholders that have been trained in other disciplines (e.g. nursing, Social Welfare) and those who have other tasks on top of - and sometimes competing with - CBR duties. A specific example of CBR workers combining different duties is the use of 'Community-based contraceptive distributors' in CBR projects in Zimbabwe. In these projects, workers had the regular task of providing information about and distributing contraceptive devices even though there was no obvious overlap between this task and CBR work. These CBR workers were most likely chosen for this unrelated task because they were reason that they have been chosen to be involved in CBR is most likely because they are already known in the community and had access to the families.

5.4 Objectives of CBR projects

In order to analyse and discuss the roles of stakeholders in CBR projects, the types of objectives that have been assigned to the different stakeholders need to be clarified. The available documentation for ten CBR projects included both the objectives and a record of the stakeholders involved. This covered a limited, but varied, number of projects in five different countries (Botswana, Lesotho, Malawi, Zambia, and Zimbabwe), and were either run by NGOs (Red Cross, Malawi Against Polio, Zimcare) or by Governments (e.g. Ministry of Health, Ministry of Social Welfare). The 'exclusion' of South Africa is noticeable. As shown in table 5.1 (page 93) a number of projects in South Africa were identified, but the documentation available was fragmented and focused on the training of Community rehabilitation workers. Thus, they only described CBR projects marginally. Also, the only project that was run by people with disabilities (Rural Membership Development Programme) failed to meet the criteria for inclusion in this study. This is unfortunate since this project demonstrated how people with disabilities themselves were able to form the structure through which the awareness and development of people with disabilities was promoted.

In table 5.3 (page 100) the objectives and the stakeholders for each CBR project have been listed. The objectives are expected to al large extent to determine the interventions made by, and the perceived roles of, the different stakeholders. Commonly, the main objectives in CBR aim directly at improving the quality of life of the person with a disability. In some practices objectives that specifically aimed at changes within the different stakeholders (e.g. increasing the knowledge of Local Supervisors) were formulated. This implies that stakeholders are not only the 'agents of change' but also 'objects of change'.

Project objectives are described as 'statements of specific outcomes that are to be achieved' (Johnson & Scholes, 2002) and as such mark the difference between an existing situation and a desired situation. However, none of the CBR projects studied presented an accurate description of the actual situation, the needs of people with disabilities, the requested support by the families, etc. Objectives set in a CBR project seem to be entirely based on a common notion of a desired situation. Lundgren-Lindquist & Nordholm (1993), for example, started with a general description of the perceived disadvantaged position of people with disabilities in

developing countries. This followed by a description of the problems such as; *"mortality rate among children with disability is higher"*, *"children with disabilities have less opportunities to attend school"*, *"adults with disabilities have lower incomes"*, and *"people with disabilities are not represented in the planning and decision making in their societies"*. These problems were not based on a factual analysis of the situation of people with disabilities in the project area, and were thus not reflected in the objectives of the projects. Consequently, these general problems could not be directly connected to the expected interventions of specific stakeholders. Although the study of Lundgren-Lindquist & Nordholm (1993) is mentioned here as a typical example of applying a broad and general perspective on people with disabilities to a specific project, this approach appears to be common in all of the studies that were included in this analysis. In analysing the objectives given in table 5.3, a few (methodological) problems become apparent. These problems are identified and discussed below. The numbers between brackets refer to the objectives listed in table 5.3.

Objectives are not specific

Objectives like 'to increase knowledge' (5.4), 'to encourage the social integration' (6.3), and 'to increase awareness' (8.1, 9.1) are indistinct as they do not specify what aspects need to be addressed and which stakeholders would be involved. Furthermore, it implies that knowledge about the baseline is available, and assumes that the means to attain the objective, and what an 'attained objective' looks like is known. None of the studies mentioned includes an actual analysis, or even a description, of awareness level, education level, and quality of life of people with disabilities or motivation to change.

Objectives are formulated as preconditions

In the process of achieving objectives, it is common and necessary to bring about appropriate preconditions and to develop procedures. These preconditions and procedures are not an objective in its own right but are to be seen as means to attain an objective. Although the difference between 'means' and 'objectives' will often be debatable, it is important that objectives be formulated as a functional or meaningful change of the situation as a result of the intervention. For example, the involvement of stakeholders (including organisations formed by people with disabilities) has been listed as a project objective frequently. In one or two projects, this seems to be a genuine objective (7.1, 9.1) but in most situations this objectives is part of establishing 'prior conditions' or 'using resources' (e.g. 1.5, 2.1, 2.2, 4.2, 9.5). Another example is the objective that aims to 'provide appliances' (1.3, 4.1). Most likely the actual objective behind it aims to 'improve mobility'. To make it even more specific it could be phrased as 'to enable the child to walk from home to school'. Also the 'establishment of an information and monitoring system' (3.3) is a means rather than an objective. In this example the objective could be rephrased as 'the development of a responsive and accountable management system to support and inform the different stakeholders'.

Objectives are not phrased in a way that they can be evaluated

The objectives have been phrased in a way that makes it impossible to determine whether objectives have been reached, to what extent and when. An objective such as *'to identify and*

Table 5.3 Overview of objectives of CBR projects and stakeholders involved

Country, Organisation, Project title, Objectives	Stakeholders involved
Botswana *Botswana Red Cross CBR programme for the disabled: Kweneng (project South) and Tutume (project North)*	
1.0 To promote community based health care and rehabilitation of disabled persons with full participation of their families and the community. Specific objectives include:	People with disabilities Red Cross volunteers
1.1 To identify and register all disabled persons	Family Welfare Educators (WFE)
1.2 To assess and programme disabled persons for rehabilitation and improved quality of life	Rehabilitation Assistants
1.3 To provide appropriate appliances	Community members / representatives
1.4 To promote placement in schools, workplaces, etc.	Teachers
1.5 To educate communities and motivate them to take an active part in CBR	Rehabilitation Social Welfare officer
1.6 To develop a system for reporting, monitoring, and evaluation of the programme	Trainer (expatriate OT) Chief training officer (headquarters)
Botswana *Ministry of Health: Special Services Unit for the Handicapped*	
2.1 To coordinate policy and ensure that every section dealing with the handicapped is aware of the official line of approach	People with disabilities Family
2.2 To liase closely with local organizations for the handicapped	Family Welfare Educators (WFE)
2.3 To maintain intimate contact with people with disabilities and caregivers	Social Welfare Officer (SWO) for the handicapped
2.4 To maintain a register of people with disabilities	Organisations, Government
Lesotho *Scott CBR project*	
3.1 To establish a CBR programme in Scott Hospital service area over a period of three years	People with disabilities
3.1.1 To introduce the concept of CBR to PHC management	Local support groups, Village health committees
3.1.2 To train 16 people who will train CBR-worker in the villages	CBR-workers
3.1.3 To support and supervise training of CBR-workers	CBR trainers
3.1.4 To establish a managerial supervision structure to establish the effective function of the programme in each area	CBR coordinator (CBR structure is integrated within PHC structure)

3.2	To motivate and assist communities in the establishment of local support groups	
3.3	To establish an information and monitoring system	
Malawi	*Malawi Against Polio (MAP): Outreach programme*	
4.1	To provide medical assistance and appliances for the victims of polio and other disabling conditions and to adopt all possible measures for their welfare	MAP physiotherapy assistant Physiotherapist / occupational therapist
4.2	In association with other voluntary and statutory bodies to take any other measures for their welfare	Orthopaedic technician MAP Unit (4) Orthopaedic surgeon Map Head Office / director
Zambia	*Zambia National Campaign to Reach Disabled Children (ZNCRDC): projects in Zambezi, Katete & Kasama*	
5.0	To enable the disabled and their families to co-exist and participate fully in the family and community activities. Seven specific objectives are given.	Health Assistants District Rehabilitation Team
5.1	To identify disabled children and stimulate rehabilitation activities within the community	Physiotherapist (expatriates)
5.2	To promote delivery of supportive and specialist services to community efforts	Special teacher
5.3	To function as part of Primary Health Care emphasising prevention and early intervention	Clinical officer of psychiatry
5.4	To increase knowledge on impairment and disability prevention	Clinical officer TB and leprosy control
5.5	To increase materials for reference and training	
5.6	To promote social acceptance of disabled children and avoid stigma	
5.7	To co-ordinate rehabilitation activities concerned with disabled children	
Zambia	*CBR programme Chipata district (1996)*	
6.1	To sensitise and educate the communities on disability issues	CBR implementing team (CBR co-ordinator, Physiotherapist, Social Worker, special teacher) Volunteers (many of them with a disability or relatives): Local CBR committees CBR planning team (thirteen people from government and NGOs of and for people with disabilities)
6.2	To empower disabled people in the home villages	
6.3	To encourage the social integration of disabled people within the community	
6.4	To train CBR workers and Rural Health Centre staff on disability issues and implementing the programme	
6.5	To provide rehabilitation services near community members	
6.6	To join the efforts and resources with others in the field of rehabilitation	

Zimbabwe *Zimcare home-based learning programme for mentally handicapped people*		
7.1	To help families living in rural areas with a home-based learning scheme for mentally handicapped people	People with a mental handicap Caregivers (mothers / grandmothers) Family Support Workers Zimcare staff
Zimbabwe *Ministry of Health CBR programme*		
8.1	To increase awareness, educate the community	VCWs / volunteers / local facilitator
8.2	To implement rehabilitation programmes at home	Rehabilitation Assistants
8.3	To stimulate involvement of community members and to use community resources	Therapists Rehabilitation Officer, Ministry of Health Referral structure: District / Provincial / Specialised centres (see Zimbabwe Red Cross)
Zimbabwe *Zimbabwe Red Cross: projects in Mutoko (1982) and Gutu (1986) district*		
9.1	To promote awareness, self reliance and responsibility of rehabilitation in the community	PHC cadre: VHWs, Health Assistants, Community Advisers, CB distributors
9.2	To mobilise, motivate and train community members including the disabled themselves to take an active part in the training	VIDCO / local government Schoolteachers
9.3	To encourage the use of simple methods and techniques which are acceptable, affordable, effective and appropriate in the local setting	Field coordinators Red Cross volunteers
9.4	To use existing local organisation especially primary health care agencies to help deliver services	Rehabilitation Assistant Regional field coordinator
9.5	To consider economic resources and gradual take-over by Government	Red Cross Headquarters Referral structure: District hospital: RA Provincial hospital: therapists / RAs Specialised centres

Zimbabwe *Children's rehabilitation Unit: Community based parents' groups*		
10.1	To educate parents on the causes, prognosis and management of their children's disability	Volunteers
10.2	To encourage the growth of group autonomy and action independent of professional participation	Rehabilitation Technicians Therapist
10.3	To encourage the growth of friendship and support among the parents	Specialised institution
10.4	To monitor the progress of the children, assist the parents in carrying out treatment programmes	Paediatrician
10.5	To refer back to the central facility for specialist attention as necessary	
10.6	To ensure follow-up of all children with disabilities in these areas through the assistance of volunteers	

register all disabled persons' (1.1) would be impossible to achieve due to definition problems and practical impossibilities. Objectives such as *'to promote placement in schools...'* (1.4) and *'to educate communities and motivate them to take an active part in CBR'* (1.5) refer to 'actions-to-be-taken' more than 'objectives-to-be-achieved'.

Objectives do not reflect or cover the contents of the project
Arnold (1995) commented in the evaluation of the Scott CBR project that the objectives did not fully reflect the project. In addition to the set of formal objectives agreed to at the start of the project, and there are other, informal, objectives. For example, in the Scott CBR project the objective 'to improve the status of disabled people within the community' is not listed in the formal objectives but came up frequently in the discussions with the project staff. Also, specific objectives set within different intervention levels might not be included in the formal objectives of the project as a whole.

To add to the criticism that many project objectives have been based on a general idea about the position and needs of people with disabilities and other stakeholders, it is mentioned here that CBR projects also introduce new objectives to communities by changing peoples' perceptions on their situation or by just becoming part of their life. This results in the creation of other demands and involuntary increases the impact of a disability on daily life by setting expectations that cannot be fully met. Not one of the projects studied here, monitored such trends or accounted for this effect.

5.5 Stakeholders' contribution in achieving objectives

In all CBR projects described, people with no professional training in rehabilitation, education, nursing, etc. have explicitly been made responsible for the training of people with disabilities. Trainers and therapists have changed from roles providing hands-on therapy or training to the people with disabilities, to roles that provide instruction to Intermediate Level Supervisors. However, this was only possible due to the introduction of 'second level' CBR workers (see table 5.2). In a comparison between CBR in Botswana and Zimbabwe, Ingstad (2001) focussed on the availability of Rehabilitation Technicians. She observed that only a few Rehabilitation Technicians were working in Botswana whereas in Zimbabwe Rehabilitation Technicians were employed in every district. According to her, the number of Rehabilitation Technicians makes the difference between a 'struggling' CBR programme (Botswana) and a 'thriving' one (Zimbabwe).
As a result of the indistinctiveness of CBR project objectives, understanding the roles of the stakeholders involved is complex. Questions such as 'who is going to sensitise and educate the communities about disability issues' need to be answered. Are objectives that focus on the community the responsibility of the stakeholders living in that community? Or is it the second level rehabilitation worker who supports the Community Rehabilitation Worker or the Local Supervisor? And, if so, does she have the knowledge to accept this responsibility and will her authority be well received in the community?

Table 5.4 Project objectives assigned to stakeholders in CBR

Summarised objectives	Objectives (see table 5.3)	People with disabilities	Family / family trainer	CBR workers: 1st level: CRW / LS	CBR workers: 2nd level: ILS / RA	CBR workers: 3rd level: trainer	CBR workers: 4th level: specialist / coordinator
To identify, assess, register people with disabilities	1.1, 1.2, 2.4, 5.1			+++	+++	+	
To train people with disabilities	4.1, 5.1, 8.2			+++	++	+	
To support families	7.1, 10.4			+++	+++		
To empower stakeholders, form support groups	6.2, 3.2, 10.3				+	+	
To provide appliances	1.3, 4.1				+	++	+++
To increase awareness / knowledge / information	1.5, 5.4, 6.1, 8.1, 9.1, 10.1				++	++	
To increase participation / integration	1.4, 5.0, 5.1, 5.6, 6.3			+++	++		
Community involvement / resources	6.4, 8.3, 9.1, 9.2, 9.3, 10.2				++		
To train 1st level CBR workers	3.1.2, 3.1.3				++		
To improve coordination between sectors	2.2, 4.2, 5.7, 6.6, 9.4				++	++	++
To develop and maintain service system	1.6, 2.3, 3.1, 5.2, 6.5, 10.5, 10.6						+++
To influence / coordinate policy level	2.1, 9.5						+++

Normative description: principal stakeholders
Normative description: supporting stakeholders
\+ Extent of involvement of stakeholders in CBR projects in Southern Africa

In table 5.4, the different objectives are grouped and assigned to the appropriate stakeholders. The symbols + (minor), ++ (moderate), and +++ (major) stand for the extent of the involvement of the stakeholders required to reach the objectives as presented in the ten projects analysed. These symbols have been positioned against a grey shaded background. The grey backgrounds in the table represent the normative descriptions of the roles the particular stakeholder play. For example Community Rehabilitation Workers are the main stakeholders involved in training the person with a disability, and this has been emphasised with a dark grey background. Supporting stakeholders (i.e. the Intermediate Level Supervisors and trainers) are placed on a lighter grey background.

Looking at the project objectives and how they have been assigned to the stakeholders, it is noticeable that the +'s and the grey shaded areas do not neatly cover the same boxes. In fact, the grey shaded areas are placed more to the left than the +'s. This implies that, in 'real-life' CBR projects, the responsibility for objectives is upheld by a higher level of stakeholder than was discussed in chapter 4. It is also noteworthy that very few objectives are assigned to the person the disability and to the family and family trainer.

5.6 Discussion

The CBR projects studied in this analysis emphasised 2nd level rehabilitation workers (Intermediate Level Supervisor or Rehabilitation Assistant/Technician). Interestingly, the two projects in which they were not included recommended the introduction of a 'mid-level' rehabilitation worker in their concluding statements. The objectives and tasks of this level are very much derived from the 3rd level rehabilitation worker: the trainer. This 2nd level cadre fits well in the professional rehabilitation network and can be seen as the most community-oriented rehabilitation worker. In practice, the 2nd level Rehabilitation Workers often work directly with people with disabilities and will involve 1st level rehabilitation workers (Local Supervisors) to assist them and to continue the training in their absence. This 'helping-hand' model does not comply with the prospected role as outlined in chapter 4.

A few comments need to be made on this study before approaching to an overall conclusion.

- The study has been limited to CBR projects in Southern Africa. The choice to only include documentation in English might have affected the inclusion of CBR projects in the non-English speaking countries Mozambique and Angola. References to CBR projects in these countries have been found, but no reports or studies that could contribute to this study could be obtained. This is regrettable, especially since these countries are, due to their recent history of (civil) war, confronted with many land-mine (and other violence-related) victims. As indicated by Ingstad (2001) and others, war can be a forceful drive to set up rehabilitation services. If and how this works out for Mozambique and Angola is unknown and therefore not included in this study.
- The documentation on quite a number of CBR projects has been disappointedly minimal. It sometimes consisted of no more than a reference made in WHO's review (2003) or in other

documents. It is therefore very hard for people interested in CBR to assess and become familiar with their projects unless they are directly involved in that specific project. This not only hampers sharing information and learning from each other, it also neglects the question of whether or not the chosen approach met the expectations of the people with disabilities as well as other stakeholders in the project.
– The inclusion of 'grey literature' made it possible to study CBR projects in more detail than would have been feasible if only peer-reviewed articles were included. However, the quality of 'grey literature' is difficult to assess because the methodology is often not robust.
– Twenty-nine articles about CBR in the Southern African region formed the basis of this study. Twenty-three articles could be related to a specific CBR project, and fourteen of these could be related to seven selected projects (for two projects no related articles could be found). In fact, nine articles stemmed from two projects (Botswana Red Cross CBR programme and Zimbabwe Ministry of Health CBR programme). Although these two projects were reasonably covered (in combination with the 'grey literature'), the overall picture was that documentation on CBR projects is scarce and fragmented and the basis for analysing the roles of stakeholders in specific projects is still small.

Although the names of stakeholders differed (table 5.3), the CBR projects described here share a very similar structure. The hierarchical pyramid of stakeholders and services, is in all of these projects, characterised by a clear co-ordinating structure headed by professionals residing in Head Offices. This managerial structure is basically identical to the ones existing in hospitals, rehabilitation centres, special education, etc., and it also conforms to the CBR structure proposed by Helander (1993, 1999). All of the projects involved referral centres (hospitals and specialised centres) at the district, provincial, and national level. None of the articles presented a negative picture or judgement on institution-based services. These services were very much used complementarily to the assistance that could be offered by CBR projects. Thus, the earlier described dichotomy between institution- and community-based services appears to be non-existent or irrelevant in 'real life' CBR projects.

First and second level of CBR workers were emphasised to be the stakeholders most responsible for project objectives. In some projects the second level CBR worker was not included. In these cases the third level CBR worker (often a therapist) appears to step into the role assigned to the second level and then takes the responsibility to work directly with the person with a disability and her family. In most projects the third level CBR worker basically supervises the second level and organises CBR at the district and provincial level. It is quite distinguishable that when finances or other resources are involved (such as in the provision of appliances), these objectives 'belong' to the third level CBR workers. None of the projects outlined a (decentralised) budget structure in which parts of the budget were made available to first or second CBR workers or even to families or the people with disabilities.

The objectives of the projects are apparently based on assumptions and on an implicit, and expectantly shared, understanding of 'what needs to be done'. At the level of the person with a disability, the starting point appears to be the development of her full physical capacities regardless of the type of activities that she wants to do. At the community level, the assumption is that low levels of awareness, knowledge, and self-reliance restrain the person with a disability

from living their life like anybody else. However, without a prior assessment of the actual situation and a description of the desired situation, setting project objectives is not only an incomplete but also insecure process. It is not only difficult to determine when the desired situation has been achieved, it is also unknown whether or not the right objectives were chosen and how relevant and effective they were in influencing the different stakeholders.

Only one of the projects listed 'empowerment of stakeholders' as an explicit objective (table 5.3 objective 6.2). However, what this implicated and what type of interventions were carried out to actually empower this group was not made clear in this project. Looking at the objectives listed, it appears that most objectives do point at increasing the competence levels of the different stakeholders involved in CBR. However, better fulfilment of roles as a result of an increased competence level does not necessarily give stakeholders the authority to influence (parts of) the project. In the projects studied, the control of resources and the power to make changes within the project stays very much with the programme implementers and the trainers and it is not handed over to the other stakeholders involved (i.e. stakeholders in the community).

It can be concluded that, although strengthening stakeholders is part of the objectives of CBR projects, the influence of stakeholders in the rehabilitation process is fairly limited, and goal-setting in addition to the allocation of resources and power occurs at the level of the programme planners.

Notes:

[1] The keywords: 'disability', 'disablement', 'rehabilitation', 'Community-based rehabilitation' have been used in different combinations and were also combined with 'developing countries', 'Southern Africa', and the names of the countries in Southern Africa

[2] To access: http://www.ids.ac.uk/data/source/source.htm

[3] For example: EENET (U.K.), DART (South Africa)

[4] Special thanks to M. Miles, B. O'Toole, A. Vreede, P. McLaren, and SCF UK who provided bibliographies and documentation

[5] Google has been used to search information available on the Internet (same keywords as in Medline)

The functioning of Rehabilitation Technicians in the CBR pilot projects in Zimbabwe

6

Abstract

Rehabilitation Technicians were trained in Zimbabwe with the original intent for them to staff rehabilitation services in district and provincial hospitals. The start of eight CBR pilot projects gave them a crucial role in the implementation and running of CBR projects in Zimbabwe. The projects were successful in identifying people who could benefit from rehabilitation and who had had no contact with rehabilitation services before. Half of the people identified had been referred to a hospital or other specialised rehabilitation service. The follow-up of people with disabilities proved to be the bottleneck of the project. Two-thirds of the volunteers that were trained for the survey and home-based training programmes dropped out within two years, and Rehabilitation Technicians did not manage to visit the communities and the people with disabilities on a regular basis. Shortage of manpower, lack of transportation, and unreliable communication were reported by the Rehabilitation Technicians as their main problems in organising home-based training programmes for the people with disabilities and maintaining an effective follow-up routine. It is concluded that the Rehabilitation Technicians are too dependent on the system of health services and the resources provided by the (district) hospitals. Also, they have copied work processes common in clinical settings and applied them to the CBR setting. It is suggested that Rehabilitation Technicians change their work process in order to become more effective. Instead of providing training directly to the people with disabilities, they should support volunteers in a consistent way, mediate between the person with a disability and specialised health services, and facilitate the development of a common interest between people with disabilities, their caregivers, volunteers, and other community members. In addition, the locus of control of CBR projects should shift towards groups in the community. As such, the CBR process will be controlled at the community level and will be less dependent on professional rehabilitation workers and less prone to logistical problems.

6.1 Introduction

Of the six stakeholders discussed in the earlier chapters of this thesis, the Intermediate Level Supervisors are the most crucial stakeholders when it comes to providing assistance to people with disabilities. They are the most community-oriented rehabilitation worker within the professional rehabilitation structure, and, as such they are the connecting link between professional services and people with disabilities, their family, and volunteers. As part of addressing research question 4 (chapter 1), a study to establish the functioning of Rehabilitation Technicians in CBR projects in Zimbabwe was carried out. The study focused on the tasks of identifying people with disabilities, referring them to specialised services, and following-up home-based training programmes.

6.1.1 Development of rehabilitation services in Zimbabwe

Zimbabwe is a landlocked country within Southern Africa (figure 6.1, page 114). It is sparsely populated with a population of 10 million (1990) spread over an area of nearly 400,000 square kilometres. The country is administratively divided into eight provinces and 55 districts. Although it is primarily an agricultural nation, mineral extraction, manufacturing, and tourism are also an important part of the country's economy. Most industry and development are concentrated in the urban areas while two-thirds of the population live in the rural areas and are predominantly concerned with small scale farming. The area which is now known as Zimbabwe was invaded by European settlers in the last decades of the 19th century. By 1895, a white legislature was established and the country was being referred to as Rhodesia. In 1964 Ian Smith became president and pressed for independence. When 'independence' was refused by the British government, he called for a 'unilateral declaration of independence' which was, de facto, a white minority-ruled government. International pressure was not sufficient enough to make Smith accept majority rule and campaigns of guerrilla warfare started around 1966 as a result of his choice. These resulted in non-racial elections and Independence in 1980.

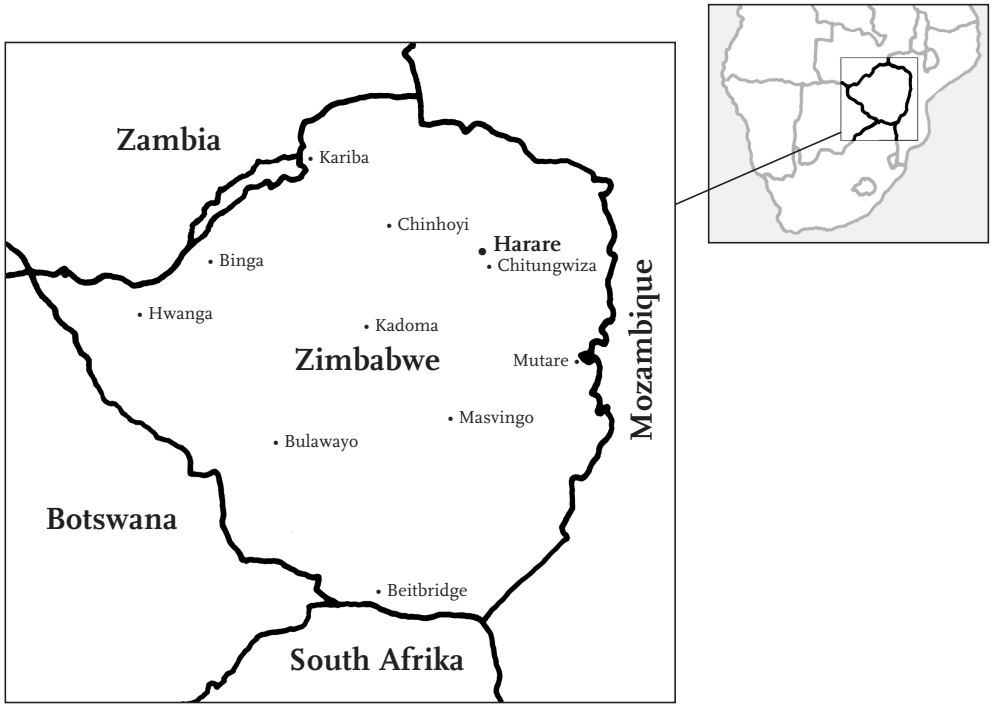


Figure 6.1 Zimbabwe

Before 1980, the government health services developed along two lines that were divided distinctly by race and class. This resulted in a service for the 'better off' and a service for the rest of the population. The first service was comparable to British hospitals while the second service was characterised by overcrowded wards, shortages of medical and nursing staff, lack of equipment and medicines, and poor hygiene. This health system was supplemented by private clinics (again for the wealthy minority) and services set up by non-governmental organisations (mission hospitals, rehabilitation centres, schools for the deaf, services for the blind, etc.) to serve the underprivileged part of the population. Another division in health care was extensively described by Mpofu (2001, 2003) when he characterised the health-care system of Zimbabwe as multi-layered: modern and traditional. The modern, or formal, health-care system is manned by professionals trained in Western methods of diagnosing and treating illnesses. The traditional, or non-formal, system consists of traditional healers and prophets (faith healers). According to his findings, these sectors hardly ever work together. The formal health system does not refer people to the non-formal system or vice-versa, although people with intractable health problems will be referred to a Western-style doctor by traditional healers. He describes the traditional system as *"the first port of call and often the last resort"*.

Before independence, rehabilitation services were largely urban-based institutional-type settings. In 1980, nine physiotherapy departments along with one orthopaedic workshop were functional in central and provincial hospitals. Since then rehabilitation services have

undergone major changes. A national disability survey, carried out in 1981, indicated that there were some 276,300 people with disabilities in Zimbabwe (equivalent to 3,6% of the population) (Ministry of Labour and Social Services Zimbabwe & UNICEF, 1982). Responding to this finding, the Ministry of Health established a unit that was to work on a comprehensive plan to ensure access to rehabilitation for all those who needed it. This would then become part of the Primary Health Care (PHC) programme that had already been developed for the country. This PHC programme included the construction of rural health centres and upgrading of existing provincial and district hospitals, an 'Expanded Programme on Immunisation' (EPI), a training programme for Village Community Workers (VCW), as well as various other programmes (Sanders & Davies, 1988).

In order to respond to the large number of people with disabilities in Zimbabwe, rehabilitation services not only needed to be decentralised, they first of all required expansion. Special emphasis was given to the development of rehabilitation cadres to man the departments in provincial and district hospitals. With the assistance of foreign donors and expatriate therapists, the training of Rehabilitation Technicians began in 1981. A few years later, a physiotherapy and occupational therapy course (BSc) was established at the University of Zimbabwe. By December 1990, 175 Rehabilitation Technicians were trained (146 of them were employed by the Ministry of Health) and sixty-five rehabilitation departments were functioning in central, provincial, and district hospitals. Once rehabilitation departments were functioning in all provincial and most district hospitals, it was felt that a move towards the community should be made.

6.1.2 Training of Rehabilitation Technicians

The training of rehabilitation staff was the Ministry's first concern in setting up adequate rehabilitation services in Zimbabwe. In addition to the more obvious difficulties associated with the training and employment of staff (costs, availability of trainers, supervision of students, etc.) two fundamental issues were considered.

- It was felt that rehabilitation workers should help families and communities to look after people with disabilities, thus reducing the dependence on professionals.
- In the past, a few Zimbabwean occupational and physiotherapists had been trained abroad. For the development of rehabilitation, however, therapists had to be recruited from Western Europe and Northern America. It was felt that they were required at central and provincial levels in order to maintain a professional standard and to facilitate the planning and administration of rehabilitation services. However, since they worked on two- or three years contracts, continuity was not secured. Also, they generally did not speak the local languages and did not share the same cultural background as the people in need of rehabilitation. Their expertise was based in a Western health care system that focused on professional care as opposed to family and community care. Thus the specialised skills that were considered to be of great value in their home countries were not necessarily appropriate for people with disabilities in Zimbabwe.

A type of cadre was required that could be trained locally, and in a relatively short time, to provide basic rehabilitation services under limited supervision. The Ministry decided to start a training for 'Rehabilitation Assistants'. The training of the first group lasted three months, but

it was later extended to a two-year course. The name also changed to 'Rehabilitation Technicians'. The entry requirement was originally three O-level passes, including English and a science subject, and in 1991 the required number of passes was increased to five. The training is broadly based as they are expected to provide services to people with a wide range of disabilities resulting from physical, mental, affective, speech, hearing, and visual disorders. The training focuses on basic rehabilitation skills and includes aspects of occupational therapy, physiotherapy, speech therapy, and social work. Function, rather than underlying impairment, is stressed. The basic assumption is that most people with a disability can benefit significantly from interventions that address problems faced in daily life, such as those of moving, dressing and eating. Also, since some problems could require more specialised care, it was suggested that Rehabilitation Technicians act as intermediaries between the people with disabilities and specialised services.

Rehabilitation Technicians are based in district, provincial, and central hospitals. The initial aim was to establish rehabilitation departments in every district and to staff each of these with two Rehabilitation Technicians. The Rehabilitation Technicians worked on the wards and outpatient clinics in addition to participating in outreach programs. In each district, the Rehabilitation Technicians received an intermittent type of supervision by the therapists who were based in provincial hospitals and a few larger, district hospitals.

The Red Cross CBR projects in Gutu and Mutoko (Zimbabwe Red Cross Society, 1987), and the Zimuto project (Budd & Mavenge, 1988) stressed the need for an intermediate cadre in CBR. With Rehabilitation Technicians based in the district hospitals, the Ministry felt that an intermediate cadre at the district level had already been created. Using a well-established cadre was seen as an advantage in the introduction of CBR to a new area. Rehabilitation Technicians know the referral systems, have links with other organisations, and are familiar with the infrastructure of the project area. Because of their professional position and their presence in the area during outreach activities they have easy access to both the official and unofficial leaders of the community. They also speak the local languages and are familiar with local traditions.

6.2 The CBR pilot projects

Following a national conference on CBR in April 1988, rehabilitation workers (Rehabilitation Technicians, physiotherapists, occupational therapists, and speech therapists) met in September 1988 to plan the implementation of eight pilot projects (one in every province). The projects would take place at the district level with district hospitals and their rehabilitation departments as a base. Health staff from the district hospitals, as well as therapists working at the provincial and national level, would facilitate the projects by, for example, assisting in the education of volunteers, the assessment of people identified in the survey, and the management of the projects. A 'CBR monitoring committee' was installed to monitor and guide the implementation of these projects. In order to account for the resources used (such as manpower and money), it was necessary to collect, aggregate, and analyse data on the projects. The guidelines for these projects included an agreement to start only in rural areas, to use one

format in the implementation of implementing CBR, and to report to a monitoring committee in a pre-set manner. As these projects were also seen as a training project for Rehabilitation Technicians involved in forthcoming projects, the projects had to be extend in time. No collective decisions were made about the population or size of the area to be covered, distance of the project from major towns, accessibility of health services, or level of prosperity in the proposed project areas. Every pilot project started with a four-week workshop (table 6.1).

Table 6.1 Format of the initiating stage of the pilot projects

Week	Day	Target group
1 Community awareness & mobilization	1	All influential members of the community
	2	Traditional midwives
	3	Community leaders
	4	Traditional healers, Church leaders
	5	School teachers
2 Training of volunteers		
3 House-to-house survey		
4 Assessment of people with disabilities		

In the first week, the education was directed towards different target groups. Apart from explaining the aims of the project and to sharing perspectives on people with disabilities, the meetings aimed at getting support from the different target groups. It was realized that some people, specifically traditional healers, were involved in the informal (re)habilitation of people with disabilities while others were in the position to regulate access to resources (i.e. school teachers, community leaders). In week two, different types of impairments and their consequences were explained to, and discussed with, the volunteers. The house-to-house survey was explained and they were trained to use simple screening forms (see figure 6.2, page 118). The survey was conducted out in the third week. Volunteers kept a register of the households visited and invited people who were 'suspect' on the survey forms to come to pre-arranged meeting-points the following week after. In the fourth week, rehabilitation teams assessed the people identified in the survey. This team included rehabilitation workers and nurses and was sometimes supplemented with other professionals (e.g. an orthopaedic technician, advisor of the council for the blind). An assessment form and treatment card was completed for each person who was expected to be able to benefit from the CBR programme. These people were provided with a home-based training plan and/or a referral to a hospital or specialised rehabilitation service. People with complaints that were not in the domain of rehabilitation (e.g. head ache, dizziness, infertility, spontaneous bleeding) were to be seen by the nurse and/or referred to a nearby clinic or hospital. The rehabilitation workers kept no records of these people.

The Rehabilitation Technician was responsible for making monthly visits to the community to discuss the progress of the home-based training plans with the volunteers, the people with

Community-Based Rehabilitation form no. ..

Survey form

CHILDREN: 0 - 14 yrs

Please ask the mother or guardian all these questions.
If there are any problems fill in this survey form and bring the child(ren) with the mother / guardian to the screening

Name of the child ..... Age of the child .....
Name of the mother / guardian .....
Ruwa / Village ..... Screening point .....
Name of Community Rehabilitation Coordinator .....

1. Was the child born before 8 months ?
2. Was your child yellow at birth ?
3. Does your child have problems with sucking or eating ?
4. Does your child - hear well ?
   - see well ?
5. Was your child in time for - sitting ?
   - crawling ?
   - walking ?
   - talking ?
6. Does your child suffer from fits ?
7. Is the behaviour of your child different from other children ?

Bring your hospital cards with you!

Community-Based Rehabilitation form no. ..

Survey form

ADULTS : 15 +

Name(s) ..... Age .....
Village ..... Screening point .....
Name of Community Rehabilitation Coordinator .....

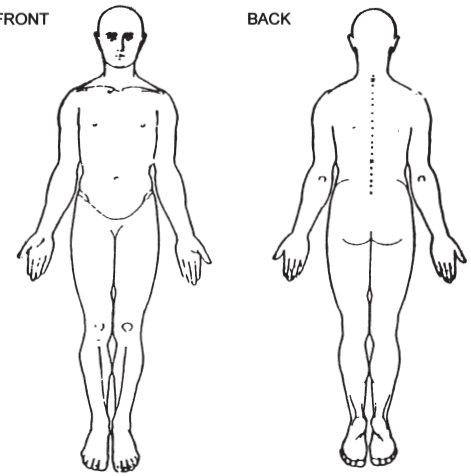
* If he/she can do it :
If he/she cannot do it :

Feed her / him self		Sit		Talk	
Wash her / him self		Walk		See	
Get dressed		.....			
Go to the toilet					

* Mark ( ) if this person's behaviour is different from others

Strange behaviour

FRONT BACK



Bring your hospital cards with you!

Figure 6.2 Survey forms (redrawn from Ministry of Health Zimbabwe, 1990a)

disabilities, and their caregivers. She would then suggest adaptations of the plan and give instructions to the volunteer and the caregiver who would continue the training in the absence of the Rehabilitation Technician. Translations of packages of the WHO manual (Helander, Mendis, & Nelson, 1983) as well as parts of other books, i.e. "Disabled Village Children" (Werner, 1987), were made available in one of the local languages. In addition, some local training materials were developed.

Eight project areas were identified and a time scheme was set. The first pilot project started in November 1988 and the eighth project in November 1989. The Rehabilitation Technicians organised the venue for the workshop, accommodation, and food for the attendants, in addition to the educational materials, etc. They provided most of the education and led the discussions during the workshop. Therapists assisted the Rehabilitation Technicians, but since most of them did not speak the local language, their input was limited. The Rehabilitation Technicians also carried out the training of the volunteers, including the explanation and organisation of the house-to-house survey. In the fourth week of the workshop they led the two or three teams that went out to the communities to assess the people identified in the survey. In one of the evaluation meetings, the Rehabilitation Technicians were called the 'backbone' of the projects. Looking at their assigned role, they really were.

As outlined above, their role includes very diverse tasks ranging from providing hands-on treatment and services to people with disabilities, educating community members, training, involving, and supporting volunteers, influencing community leaders, monitoring the project, accounting for resources used and time spent, etc.

The current study has been limited to three aspects of the functioning of the Rehabilitation Technicians. These aspects include the identification, referral, and follow-up of people with disabilities and they lead to three sub-questions.

Identifying people with disabilities

The first phase of the projects very much emphasised the identification of people who could benefit from rehabilitation intervention. In the preparation of the pilot projects, it was emphasised that CBR should not to be limited to people with physical disabilities and that interventions should adopt all possible measures to facilitate the participation and integration of people with disabilities. It was also stressed that people with disabilities and their families should not be seen as passive receivers of help but as active participants supported by community members and rehabilitation workers. In order to determine whether and to what extent, these expectations were met in the pilot projects, the question set for this study was:

> *Have the Rehabilitation Technicians succeeded in identifying and involving people with disabilities?*

Referral of people with disabilities

The CBR projects in Zimbabwe were inserted into a medical and rehabilitation infrastructure in which institutional services were able to serve as excellent referral centres (Hanekom, 1983). This system of referral made it possible for people with disabilities to have access to the level of specialised rehabilitation treatment she required (Hanekom, 1988a). In a report about a CBR

project that preceded the eight pilot projects, Budd & Mavenge (1988) concluded that many people with disabilities had been referred to institutional services after the screening, but many people did not attend the place they were referred to. This finding, combined with the fears of the referral centres about high numbers of people wanting to attend their services and the concerns expressed by the Rehabilitation Technicians about the possibly unrealistic expectations of the people with disabilities regarding the assistance that could be offered, was the reason to carry out an additional study in one of the pilot projects. The research question formulated was:

> *To what extent have people with disabilities been referred to, and made use of, specialised services, and have they perceived these visits as beneficial?*

Follow-up on people with disabilities

In the Zimbabwe CBR projects, the Rehabilitation Technicians and other health staff trained the volunteers at the initial CBR workshops. The aims of the training were to gain familiarity with CBR and to carry out a house-to-house survey to identify people with disabilities. After the implementation of the CBR projects, the Rehabilitation Technicians and volunteers were given the task of conducting a follow-up the people identified in the survey. In CBR, the most common format for a follow-up is a home visit by the Rehabilitation Technician or volunteer. For this type of follow-up procedure, Rehabilitation Technicians were, like any other district health staff, dependent on shared transport. They usually joined teams of the `Expanded Programme Immunization' on outreach missions. The following question has been formulated to evaluate these follow-up visits:

> *Have follow-up visits been conducted with the people with disabilities identified in the CBR projects?*

6.3 Methods

The Rehabilitation Technicians were required to systematically collect data on the project area, the workshops, the survey, and the progress of the projects. The type of data to be collected, the feasibility of getting reliable data and the system by which to record these data was discussed in meetings between the Rehabilitation Technicians, therapists at the provincial level, and the CBR monitoring committee. The minutes from these meetings were used to supplement these data in a more qualitative manner. The data were collected and aggregated by hand (in the field) and later analysed using Excel, EpiInfo, and SPSS 11.0.

In this thesis three partly overlapping studies were carried out. All of these studies used the data collected during the initiating stages of the eight pilot projects in addition to and the data gathered during the first eighteen months of every project. The first study is entirely based on these data, and additional research was been carried out in selected pilot projects to provide he data for the second and third study.

Study 1. *Identifying and involving people with disabilities*

This study is entirely based on the data collected in the initiating stages (see figure 6.2 page 122) of the eight pilot projects.

Study 2. *Referral of people with disabilities*

A research study that involved one of the pilot projects was carried out. The records of all of the people who were identified in the CBR project were examined based on the type of intervention offered (referral and/or home-based training programme), and a sample of the people who had been referred were interviewed using a semi-structured questionnaire.

Study 3. *Follow-up of people with disabilities*

A study that evaluated the follow-up visits conducted on 5-14 year old children was carried out. In addition to the data from these children's records, information for the study was obtained from interviews with the Rehabilitation Technicians, volunteers, and caregivers of the children. 'Practice interviews' were conducted easily-accessible areas. Subsequently three project areas were chosen to carry out this study. Volunteers and caregivers were only selected for an interview if the child had been seen by the Rehabilitation Technician at least three times. Children with all types of disabilities were included. A structured form was developed to collect information on age, sex, diagnosis, action taken at screening, and follow-up visits. This information was copied from the CBR project records. Sometimes additional information was found in other registers kept in the hospital by rehabilitation or other health staff (outreach register, disability register, etc.). Semi-structured interviews were conducted with the Rehabilitation Technicians, volunteers, and caregivers. The interviews carried out with the volunteers and caregivers covered some of the same issues, but the interviews conducted with the volunteers were more comprehensive.

6.4 Results

The results of these studies will first be presented separately and later discussed in relation to each other.

6.4.1 Identifying and involving people with disabilities

The four-week workshops were perceived as successful in all eight projects. The first week of the workshop was well attended by members of the different target groups; in two projects more than 600 people attended the first day. Discussions between rehabilitation workers and attendants were lively. The attendants were positive about the project and expressed a willingness to work together, to inform people with disabilities about the project, and to refer them to the rehabilitation workers as needed. This specifically applied to traditional birth attendants and traditional healers as they would see many people with disabilities in their practice.

A total of 571 volunteers were trained in the second week. Of these, 253 of them were already active as a Village Community Worker, and 179 were trained as a Red Cross Volunteers. The volunteers were instructed to use simple survey forms for the house-to-house survey.
The results of the survey and assessment are presented in table 6.2.
Looking at projects B, C, D, E and F (A, G, and H are excluded here because of unreliable or missing data), every volunteer visited 30 households on an average. In three projects the volunteers counted the total number of people in the households. Their findings indicated that every household consisted of an average of 5.3 people.

Table 6.2 Results from the house-to-house surveys and assessments

	House-to-house survey				Assessment		
Project	Nr. of volunteers	Nr. of households	Nr. of people contacted	Identified for assessment	Attending assessment	Benefit from intervention	Already known
A	116	~~220~~	–	234	171	154	35
B	83	1790	13222	–	598	99	1
C	38	1410	–	400	376	45	5
D	95	1238	–	–	749	256	~~2~~
E	65	3084	19771	611	377	252	12
F	40	1976	15559	289	279	177	25
G	84	–	–	–	659	325	26
H	50	–	–	505	422	306	–
Total	**571**				**3631**	**1614**	

– Missing data
~~2~~ Data presented with a double strikethrough are considered unreliable and have not been used in calculations.

Nearly 80% of the people who were identified by the volunteers attended the screening, and 1614 people, or 45% of the people attending, were assessed as being able to benefit from rehabilitation intervention. If this result is compared with the estimated 90,000 to 105,000 people visited in their homes, it can be concluded that the survey and the screening have identified that 1.5 to 1.8% of the population has a disability and could benefit from rehabilitation intervention. Very few of these people had been in contact with rehabilitation workers before. In table 6.3 the people identified for intervention are presented by age group and condition.

To investigate whether the people identified in the CBR projects differ in disabling condition or age from the people seen in rehabilitation departments in the hospitals (including outreach services), the findings of the survey have been compared with data from rehabilitation departments in the hospitals (tables 6.4 and 6.5, page 124). Results from the Disability Survey (Ministry of Labour and Social Services Zimbabwe & UNICEF, 1982) have also been included

Table 6.3 People identified for rehabilitation intervention (n=1614)

Disabling condition		Age groups 0 - 4	5 - 14	15 - 49	50+	**Total**	%
Neurological disorders							
Cerebral palsy		36	58	16	3	113	7.0
Adult hemiplegia		–	–	45	33	78	4.8
Paraplegia		2	1	12	9	24	1.5
Polio		0	34	47	8	89	5.5
Other neurological disorders		19	46	52	24	141	8.7
Orthopaedic disorders							
Amputation		2	4	31	17	54	3.4
Rheumatoid arthritis		0	2	5	14	21	1.3
Clubfeet		11	22	11	1	45	2.8
Other congenital disorders		4	13	23	6	46	2.9
Other orthopaedic disorders		6	49	88	57	200	12.4
Medical disorders							
Respiratory disorders		5	19	19	15	58	3.6
Other medical disorders		2	10	26	47	85	5.3
Cognitive, sensory disorders & developmental delay							
Mental handicap		15	87	66	2	170	10.5
Psychiatric disorders		2	7	67	22	98	6.1
Developmental delay		31	34	2	0	67	4.2
Hearing and speech problems		19	85	64	11	179	11.1
Vision problems		4	4	33	41	82	5.1
Other cognitive or sensory disorders		1	12	24	27	64	4.0
Other disorders		0	0	0	0	0	0.0
Total	**n**	**159**	**487**	**631**	**337**	**1614**	
	%	*9.8*	*30.2*	*39.1*	*20.9*	*100*	

in the table. To make comparisons possible, the data had to be regrouped (for the CBR projects) or combined (for the Disability Survey).

6.4.2 Referrals

Data from the initiating stage of the projects indicated that 35% of the people identified were referred to a clinic or hospital, and 45% were referred to specific rehabilitation services (i.e. eye clinics, medical specialists, orthopaedic technicians). However, these categories were not mutually exclusive and the data are partially overlapping. As such, the actual number of people

Table 6.4 Disabling condition of people with disabilities seen in CBR project and in hospitals, Zimbabwe (n=1614)

	CBR projects 1988-1989		People with disabilities treated in hospitals, 1988	Disability survey, 1982
Disabling condition	n	%	%	%
Orthopaedic disorders	366	22	53	45
Neurological disorders	445	28	18	
Medical disorders	143	9	20	2
Mental retardation, developmental delay	237	15	4	10
Psychiatric disorders	98	6	2	
Hearing and speech problems	179	11	–	16
Visual problems	82	5	–	25
Multiple disabilities	0	–	2	–
Others	64	4	1	2
Total	**1614**	100	100	100

Table 6.5 Age of people with disabilities seen in CBR project and in hospitals, Zimbabwe

	CBR projects 1988-1989		People with disabilities treated in hospitals, 1988	Disability survey, 1982
Age groups	n	%	%	%
0 - 4	159	10	17	5
5 - 14	487	30	20	(5-15) 20
15 - 49	631	39	42	(16-59) 21
50+	337	21	21	(60+) 24
Total	**1614**	100	100	100

referred could not be established from these data. Therefore, an additional study was carried in one of the pilot projects (project E). In this project, 243 people with disabilities were identified in the initiating phase of the project and in the following 18 months (up to January 1991), 167 new people entered the programme (see table 6.6). These people were seen during visits by the Rehabilitation Technicians to the communities involved in the project. The Rehabilitation Technicians also reported that they 'transferred' records of people already known before the

pilot project to the CBR register as their follow-up took place in the community. Attempts were made to record data on deceased people with disabilities but since the Rehabilitation Technicians were informed with delay or not at all these data are not expected to resemble the factual figures. No data are available on discharged people with disabilities. In total, records of 375 people with disabilities were accessible.

Two main intervention groups can be distinguished:

Y People with disabilities who were referred to hospital or specialised rehabilitation services (often in combination with a home-based training programme).

Z People with disabilities who were offered a home-based training programme (not in combination with other interventions).

As shown in table 6.6 and 6.7, group Y consisted of 177 people and group Z of 198 people.

Table 6.6 Number of people with disabilities referred (n=375)

	Initiating stage July 1989		People added to the CBR records August 1989 – January 1991				Intervention groups (March '91)				**Total**	
							Y: referral		Z: home-based tr.			
	n	%	n [1]	- [2]	Cum. [3]	%	n	%	n	%	**n** [4]	%
0 - 4	24	*9,9*	44	- 2	66	*16,6*	34	*9,1*	42	*11,2*	**76**	*20,3*
5 - 14	99	*40,7*	55	- 2	152	*37,6*	56	*14,9*	52	*13,9*	**108**	*28,8*
15 - 49	81	*33,3*	60	- 2	139	*34,4*	56	*14,9*	69	*18,4*	**125**	*33,3*
50+	39	*16,0*	8	- 1	46	*11,4*	31	*8,3*	35	*9,3*	**66**	*17,6*
Total	**243**	*100*	**167**	- 7	**403**	*100*	**177**	*47,2*	**198**	*52,8*	**375**	*100*

[1] The age of 125 of the 167 new people with disabilities was determined correctly. The rest have been extrapolated to the total number.

[2] No age was recorded for the deceased people. The total number (7) has been divided proportionally to different age groups. No data on discharged people with disabilities are known.

[3] With inaccurate data on discharged and deceased people, this cumulative count is likely to be an overestimation of the people involved in the project.

[4] Six records of people receiving home-based training only did not include the age of the person with a disability. These have been proportionally divided (1-2-2-1) over the age groups in the columns 'Total' and 'Z': home-based training.

Data on adolescents and adults (15-49) and elderly (50+) people with disabilities were consistent between the people identified and the total research population. However, this is not the situation for children. Although the cumulative percentages for the age groups 0-4 years and 5-14 years are about the same for the initiating stage (50.6%), 'new' people with disabilities (54.2%) and the research population (50.1%), the differences between these two groups are noticeable. In fact, the record studies showed more children of 0-4 years than were expected according to the information collected to monitor the projects. There is no obvious explanation for this.

The 375 records included 221 boys/men and 154 girls/women (table 6.7).

Table 6.7 People with disabilities involved in project E by type of intervention and sex (n=375)

	Intervention groups					
	Y: referral		Z: home-based tr.		**Total**	
Sex	n	%	n	%	**n**	%
Male	109	29,1	112	29,9	**221**	58,9
Female	68	18,1	86	22,9	**154**	41,1
Total	**177**	47,2	**198**	52,8	**375**	100

In figure 6.3, the intervention groups Y and Z in relation the disabling condition. People with 'polio', 'other congenital deformities', 'speech problems' and 'vision problems' appear to have been referred more frequently while people with 'adult hemiplegia' and 'developmental delay' were less frequently referred to other services.

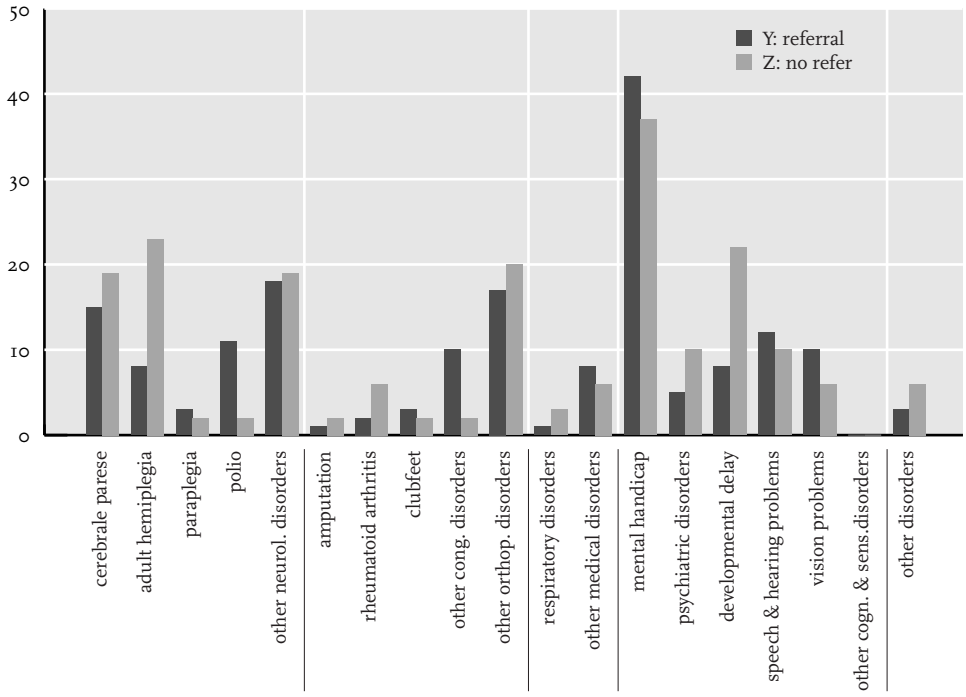


Figure 6.3 Intervention groups Y and Z per disabling condition (n=375)

Judging from the high proportion of people referred, the success of this CBR project depended to a large extent on the results of the referrals. To examine the beneficial effects of these referrals a home interview was arranged with people who had been referred to medical or specialised services. Given the large distances between the homes of the people and the time available, a few areas were selected and a random sample was taken within this area. In total 47 people were selected for an interview. From these people, four people had died since the Rehabilitation Technician saw them for the last time, and thus a total of 43 people could be interviewed (table 6.8). The interviews were semi-structured and were carried out with the assistance of a local interpreter.

Table 6.8 Age and sex distribution of the people interviewed (n=43)

	Sex		Daily occupation			**Total**	
	Male	Female	None	School	Work	n	%
0 - 4	3	1	4	–	–	4	9,3
5 - 14	10	1	6	5	–	11	25,6
15 - 49	11	4	4	1	10	15	34,9
50+	10	3	8	–	5	13	30,2
Total	**34**	**9**	**22**	**6**	**15**	**43**	100

Children (age groups 0-4 and 5-14) as well as girls and women seem to be underrepresented in the sample. With regard to daily occupation, six children were attending school while 6 others in the age group 5-14 yrs did not go to the school. Most adults reported having some kind of a job. This included peasant farming, crafts, and small business.

The people were asked if they went to the referral centre, what happened and if they thought it was beneficial to them. Their responses are summarised in table 6.9.

Table 6.9 Response of people referred (n=43)

Yes, referral was made	32	No, we did not go	11
What happened?		Reason non-compliance	
Surgery	2	We didn't know	3
Advice	6	They had to visit us but didn't	5
Medication	13	It won't help	1
Appliances	4	No money for transport	2
Financial assistance	2		
Nothing	5		

Thirty-two of the 43 people (74%) actually went to the referral service. A third got medication (i.e. painkillers or anti-epileptica), and five people reported that they got nothing out of it. Eleven people did not make use of the referral services. Only two people expressed concern about the costs to go to this service, and eight people said they did not understand or did not agree with the referral.
Based on the interviews, it appears that two-thirds of the people that went to the referral service felt that they had benefited from the referral. Ten people reported that they had seen no change. Six of them reported to have received medication which did not help, three of them were given advice that they did not perceive as useful, and one person was issued a wheelchair but the family reported that they had no time to push him around. Finally, one client who had received surgery as a result of the referral reported that he was dissatisfied because he had not been breathing properly and his stomach was swollen since the operation.

6.4.3 Follow-up

To assess the extent of follow-up of clients after their inclusion in the project, data collected by the Rehabilitation Technicians in the first eighteen months of the projects were analysed. There were 127 'monthly report' forms (88%) available for analysis. Seventeen forms could not be found. This could partly be due to the fact that no activities took place and thus the Rehabilitation Technicians did consider it useful to fill in a form and partly because some forms never reached the monitoring committee and copies were not available. In the follow-up phase, people who had not been identified in the initiating stage, or did not attend the assessment sessions, were included in the CBR project (table 6.10).

Table 6.10 People initially identified and people included in the follow-up phase of the project

Project	Initially identified	Included in the follow-up phase (first 18 months)
A	154	138
B	99	40
C	45	126
D	252	66
E	256	163
F	177	42
G	325	82
H	306	76
Total	**1614**	**751**

This table shows that during the first eighteen months after the initiating stage of the project many more people joined the CBR project. This suggests that the original survey was incomplete, and that the earlier conclusion that 1.5 to 1.8% of the population has a disability

and can benefit from rehabilitation needs to be revised. Unfortunately, the total number of people included in the project could not be calculated as the record keeping on discharged or deceased people with disabilities was incomplete.
The number of people with disabilities that were followed up per month is shown in table 6.11.

Table 6.11 Number of follow-up contacts made by the Rehabilitation Technician in the first 18 months of the project

Project	(start)	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	Average per month**
A	Dec. '88	13	40	47	23	38	23	56	38	61	35	20	12	0	31	23	13	28	*	26.8
B	Mar. '89	0	56	18	14	0	27	14	0	0	0	3	25	0	40	0	3	8	6	11.9
C	May '89	9	11	3	8	4	3	5	8	20	18	19	21	8	37	9	11	20	*	10.9
D	July '89	36	6	20	5	24	17	21	9	25	53	14	15	9	5	9	6	6	10	16.1
E	July '89	16	14	33	27	15	41	39	32	24	39	29	59	36	32	32	44	11	*	28.1
F	Oct. '89	25	20	21	21	45	26	21	16	15	11	14	27	16	6	15	9	28	20	19.8
G	Oct. '89	143	39	63	42	36	9	*	*	9	3	*	*	9	*	*	*	*	*	10.6
H	Dec. '89	*	*	*	19	15	*	25	14	5	5	11	9	5	*	28	33	23	13	6.4

* missing value
** average per month: missing values have not calculated
raining season

Averages per month for the eight projects are presented in the last column. The number of follow-up visits was unevenly distributed over the eighteen months that this study covered. Two patterns can be discerned. During the planting and raining season (November-March) less follow-up contacts were made than in other months (22.1 and 20.1 contacts per month respectively). This is probably due to the fact that, during the planting season, people are rarely at home and in the raining season any rural programme will be very much affected by inaccessibility of the rural areas. It also appears that follow-up visits in the first nine months (23.8 contacts per month) were more frequent than in the second half of the study (17.8 contacts per month).

People with disabilities who were involved in the programme were contacted at home, mobile clinics for the Extended Programme of Immunization (EPI), or at the rehabilitation department in the district hospital (table 6.12, page 130). The mobile clinics were planned once a month for the different areas in the district. Rehabilitation Technicians joined the transport arranged for these clinics and tried to make some home visits once they had reached the project area.
Two-thirds of the follow-up contact made by the Rehabilitation Technicians took place in or nearby the home of the person with a disability. Some Rehabilitation Technicians reported that they managed to find additional transport opportunities to visit the people involved. In project E, the Rehabilitation Technicians joined the 'Save the Children' campaign, and in project G the Rehabilitation Technicians borrowed a car for the first five months of the project. When this

Table 6.12 Places of follow-up contact (in %)

Project	Home visits	Mobile EPI clinics	Rehabilitation dept.	Other
A	33.0	55.1	5.3	6.7
B	12.8	59.6	27.7	0.0
C	26.8	18.7	44.4	10.1
D	27.8	30.9	39.2	2.1
E	59.4	19.3	19.8	1.5
F	35.3	32.1	27.9	4.7
G	51.8	38.6	6.0	3.6
H	17.4	6.3	76.3	0.0
Total	**34.8**	**33.4**	**28.1**	**3.7**

vehicle was withdrawn the programme more or less collapsed. No transport was available in project H, and the Rehabilitation Technicians encouraged the people with disabilities to come to the district hospital for follow-up visits. Travel to district hospitals often involved long hours, overcrowded buses, and money to pay the bus fares.
In addition to the data collected through the Rehabilitation Technicians of the projects, a more

Table 6.13 Follow-up visits of children with disabilities (5-14 years) per project (n=430)

CBR pilot projects			Children included in the study (September, October 1991)				Children with follow-up		Average nr. of follow-ups per year[2]
Project	(start)	Months[1]	Boys	Girls	Unknown	**Total**	n	%	
A	Dec. '88	34	20	16		**36**	21	*58*	1.68
B	Mar. '89	30	15	7		**22**	19	*86*	1.18
C	May '89	28	4	9		**13**	4	*31*	0.75
D	July '89	26	19	21	4	**44**	27	*61*	1.81
E	July '89	26	55	29	1	**85**	41	*48*	1.29
F	Oct. '89	23	28	19		**47**	30	*64*	1.32
G	Oct. '89	23	46	26	1	**73**	35	*48*	1.07
H	Dec. '89	21	57	49	4	**110**	41	*38*	1.02
Total			**244**	**176**	**10**	**430**	**218**	*51*	**1.27**

[1] Months between start project and study
[2] Average does not include subjects who had no follow-up visit

detailed study was carried out. For practical reasons the study focused on one age group: children between 5 and 14 years of age. In the CBR projects 487 children aged 5-14 years were initially identified (table 6.3). For this research study, 430 records of children identified in the initiating stage could be analysed. Fifty-seven records (12%) could not be found. In table 6.13, information about the population included in the study and data on the follow-up visite are presented.

Both the data collected by the Rehabilitation Technicians on a monthly basis and data from this research study show that only half of the children were followed-up. This differed very much per project, both in absolute numbers (e.g. in project C only 4 children were followed-up and in projects E and H, 41 children) and in percentages (between 31% and 86%). To find out if children with certain conditions were followed-up more than others, figure 6.4 has been constructed.

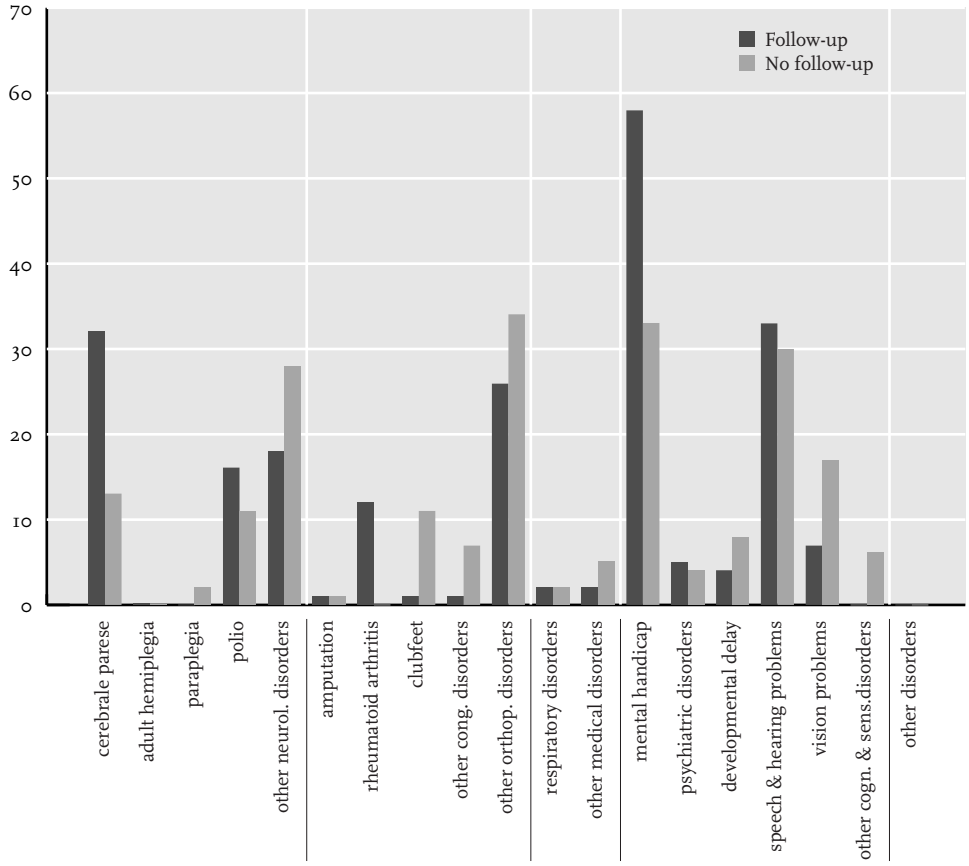


Figure 6.4 Follow-up of people identified per condition (n=430)

Figure 6.4 suggests that children with 'cerebral palsy' and 'mental handicap' have had a more intensive follow-up than other children. Children with 'clubfeet' and 'vision problems' were seen less frequently.
The Rehabilitation Technicians reported that the main constraints in conducting follow-up visits were inadequate manpower, transport, and communication, combined with the high drop out rate of the volunteers.

The drop out of volunteers was confirmed by the Rehabilitation Technicians of all projects. Two to three years after the start of the projects, two-third of the volunteers were no longer active (table 6.14). In the pilot projects, 571 volunteers were trained in the workshops. A large number of volunteers participated only in the survey and were not involved in the training of people with disabilities. Others dropped out during the follow-up phase.

Table 6.14 Volunteers trained and active after two years

Projects	Initially trained	Active two years later			**Total**
		Village Workers Community	Red Cross volunteers	Other	
A	116	0	7	–	**7**
B	83	14	0	10	**24**
C	38	*	*	*	*
D	95	9	13	0	**22**
E	65	43	0	0	**43**
F	40	18	0	0	**18**
G	84	*	*	*	*
H	50	46	0	0	**46**
Total	**571**	**130**	**20**	**10**	**160**

* No numbers could be given since the RTs in these projects have not been able to visit the project area regularly and to stay in contact with the volunteers

Rehabilitation Technicians, volunteers, and caregivers were interviewed on their experiences with the follow-up of people involved in the project. The results of these interview are summarised in the following paragraphs

Interviews with Rehabilitation Technicians
The Rehabilitation Technicians recognised that the follow-up of identified people with disabilities was a major problem in the projects. In most districts the Rehabilitation Technicians depended on shared transport which restricted regular visits to the people with disabilities. In only two districts, motorcycles were available for use during follow-up visits. According to the Rehabilitation Technicians, a number of people with disabilities were 'lost' due to this lack of

follow-up. Also, the number of volunteers initially trained and actively involved in CBR diminished drastically in most districts. Lack of incentives for volunteers and lack of time for Village Community Workers were most frequently stated to be the main reasons for drop-out or for being less active. According to the Rehabilitation Technicians, most home visits were conducted by the volunteers, but no proper registration of those visits was kept.

Interviews with volunteers and caregivers

In total, twelve pairs of caregivers and volunteers were interviewed. Most of them were visited in their homes. Ten of the volunteers interviewed were involved in CBR from the beginning and had attended the initial workshops. The other two joined during subsequent CBR workshops. Most of the volunteers reported having regular contact with the Rehabilitation Technicians. Nine reported having this contact at least once a month. However, for four volunteers the contact had been less frequent lately.

Eight volunteers stated that they visited the family one or more times a month, and this was confirmed during the interviews with the corresponding caregivers. In the four other cases the volunteers' and caregivers' answers concerning the frequency of the visits were inconsistent. Most volunteers said that the child's disability and their rehabilitation possibilities were explained to the caregivers either by the volunteers themselves or by the Rehabilitation Technician. However, four caregivers could not recall receiving an explanation of the disability, and only nine caregivers said they were informed about rehabilitation possibilities. Most volunteers found it difficult to explain the short-term goals of home-based programmes.

All caregivers received instruction on what to do with the child. Three caregivers said that the Rehabilitation Technician had given the instructions while the volunteer only made home visits to check up on the child. When the volunteers were asked whether they thought the caregiver understood the instructions, all volunteers answered in the affirmative. However, when the caregivers were asked what was actually done with the child, the answers satisfactorily corresponded with the instructions given by the volunteers in only five cases. Most caregivers said they had enough time to give the child special attention. In nine cases the volunteer as well as the caregiver answered without hesitation that the child had improved due to the home-based rehabilitation programme.

6.5 Conclusion and discussion

The study presented here is a compilation of three descriptive studies carried out in the CBR pilot projects in Zimbabwe. Interpretation of the findings has to be done prudently because the records on people with disabilities identified in the CBR project were not complete and accurate (e.g. sex, age, condition, or follow-up visits were not recorded) and the total numbers of people involved per project (as reported by the RT) could not be fully confirmed in a recount. Also, since the second and third studies involved one and three pilot projects, respectively, generalisations between the findings of these studies to all projects should be made with care. The results of the three studies will be discussed here, first per study and then together in the context of the CBR pilot projects.

Have the Rehabilitation Technicians succeeded in identifying and involving people with disabilities in the pilot projects?

The workshops at the start of each pilot project were well attended, and, judging from the lively discussions, people were interested in CBR. Large groups of volunteers were trained, and these volunteers were motivated to carry out the house-to-house survey and to accompany people with disabilities to the assessments. However, active participation by the volunteers faded away in the follow-up phase of the project. Two-thirds of the volunteers dropped out completely. The commitment of other influential community members, as shown in the first week, has not solidified into more or less organised structures to improve the participation of people with disabilities. Incidentally, Rehabilitation Technicians have reported that community CBR committees were set up but their influence was limited. Also, a few income generating projects were set up for people with disabilities, but apparently these were dependent on external funding and management. People with disabilities were the beneficiaries of the programme, but they did not really participate in the management of the programme. Organisations of people with disabilities (i.e. the National Council of People with Disabilities in Zimbabwe: NCDPZ) were informed about these CBR projects, but they were not given any power to influence the projects. Occasionally, people with disabilities were invited to tell their life-story in the workshop to illustrate the problems people with disabilities might face in addition to presenting them as a role model. It can be concluded that many people in the community were contacted but real involvement of people with disabilities has not become visible.

Volunteers conducted the house-to-house survey. Excluding practical reasons such as the limited availability of professional rehabilitation workers and the number of households to visit, it was thought that volunteers would have easier access to the families. On the other hand, this set up made it difficult to control the survey, quantitatively and qualitatively:

– It can be estimated that the volunteers visited about 45% of the households in the project areas. It is not clear on which basis they selected these 45%. The Rehabilitation Technicians suggested that the volunteers only visited households in they knew one of the family members had a disability, or that they only visited households which were relatively easily accessible.
– There was no control regarding the quality of the survey. The training of the volunteers was very basic. They might have overlooked people with minor impairments or disabilities (e.g. partial deafness, mild mental retardation). Also impairments which had not yet led to major limitations may have gone unnoticed.

It is important to stress that the aim of the survey was to identify people who could benefit from rehabilitation interventions and not to count all the people with disabilities. Also, people with disabilities who were functioning well and were integrated into the community, or people who were not expected to improve from interventions, were not included. These judgements were left to the individual Rehabilitation Technician and therapist. No standardised selection criteria were set for the survey, thus, inter-personal differences affected whether or not the person assessed was to offered rehabilitation services. As a result, comparing the data from the CBR pilot projects with other available data available should be done with caution. A few more reasons to approach data comparisons carefully are mentioned here:

– Lack of consensus regarding the use of one system of 'diagnostic categories' impaired the interpretation of the data gathered. Registration by 'condition' as done in the CBR pilot projects and rehabilitation department in the hospitals cannot be easily compared with a 'disability-oriented' classification as is used in the Disability Survey of Zimbabwe and promoted by the WHO.
– Rehabilitation Technicians had problems classifying people with disabilities. For example, a child who had been developing slowly and speech had not developed speech skills according to her age was classified under 'mental retardation' by one Rehabilitation Technician while another classified this child under 'hearing or speech problems'.
– In a country with rapidly developing health services like Zimbabwe, time can be an important factor. The Disability Survey was carried out in 1981. Nearly ten years later, the survey as part of the CBR projects was carried out. With improvement in health care, the incidence of preventable disabling conditions such as poliomyelitis may have decreased in the time between the Disability Survey and the CBR pilot projects, but, on the other hand, more children with disabilities might have survived due to better health care.

Standardisation of the classification of disabilities is needed to compare the findings of the different studies. In the past twenty years, the WHO has developed an International Classification of Functioning (WHO, 2001) and it is expected that this method will provide the required standardisation.

This study pointed out that many additional people entered the CBR projects during the follow-up phase. This suggests that the surveys may not have been complete although it might also be possible that people from adjacent areas entered the project during this phase.

It can be concluded that the Rehabilitation Technicians succeeded in identifying and involving many people with disabilities in the CBR projects. The survey conducted during the CBR pilot projects showed that many people with disabilities in the rural areas had not found their way to the (decentralised) rehabilitation services offered in the provincial and district hospitals. No information is available regarding the coverage of the survey. The high numbers of people entering the project during the follow-up stage suggest that the survey was not exhaustive. Also, not all of the people with disabilities in the area were contacted, specifically people with hearing or speech problems, vision problems, psychiatric disorders or people with a mental handicap.

To what extent have people with disabilities been referred to, and made use of, specialised services and have they perceived these visits as beneficial?

In the project studied, nearly half of the people identified for rehabilitation intervention were referred to a hospital or specialised rehabilitation service. No clear pattern of referrals (according to age, sex, or type of disorder of the people with disabilities) could be established, although people with 'polio', 'congenital deformities', or 'speech problems' appear to have been referred more frequently. This is most likely this is due to the apparent need of orthopaedic appliances or, in the case of speech problems, the availability of two speech therapists from a nearby hospital. As such, the study provided no clear insight into the reasons referring people with disabilities. When asked the Rehabilitation Technicians reported that, in most cases, they referred people who had never before been seen by a medical doctor or specialist. However,

medical histories were rarely recorded in the project files, so this could not be confirmed in this study.
The results of the study indicated that most people (74%) who were referred did visit the referral centres. This would suggest that it is possible to build on an existing network of services in CBR projects, but, a generalisation of this finding with regard to other CBR projects in Zimbabwe cannot be made easily as this particular project area was close to the capital city and its facilities. The distances to these facilities were less than in the other project areas and therefore transport was less expensive and less time consuming. Two-thirds of the people who visited a referral centre perceived the visit as beneficial, but they also pointed out that a follow-up visit was needed (i.e. when they were given medication or an orthothesis). These numbers imply that approximately half of the people referred to a centre got the assistance that they needed or expected.

Has follow-up of people with disabilities identified in the CBR projects been realised?

The follow-up of people identified in the project has proven to be the bottleneck of the project. In a study conducted specifically on children of school-going age, only half of the children were followed-up by the Rehabilitation Technician, and these children were, on average, only seen once a year. No differences according to the type of intervention (referral or home-based programme) could be distinguished, but children with 'cerebral palsy' and 'mental handicap' appear to have received more follow-up visits than children with other conditions.
The follow-up visits conducted by volunteers were not recorded systematically. Volunteers were expected to conduct these visits to advise and to train the people with disabilities and their caregivers. The major reduction in the number of volunteers that occurred between the initiating stage and the follow-up phase of the projects caused serious problems for the follow-up of people with disabilities. The drop out of many volunteers has been attributed to an insufficient communication between the Rehabilitation Technicians and the volunteers.
The interviews held with volunteers who were still active revealed that the volunteers were not clear about their role in the follow-up phase of the project. It seems that the role of the volunteers in the home-based training was rather passive and instrumental. The Rehabilitation Technicians gave instructions about the training, and the volunteer were more or less expected copy the exercises.
Given such a limited follow-up of people with disabilities, it is hardly possible to assess the home-based programmes, and it is feared that the instructions given to the volunteers at the assessment in the initiating stage have faded or lost importance over time. In this study, an impression of the functioning of home-based programmes was gained on the basis of interviews with twelve pairs of caregivers and volunteers. In these interviews, inconsistency was found between the instructions given by the volunteers and what the caregivers actually did. Some caregivers could not at all or only partly recall the instructions given by the volunteers.
A positive interaction between caregiver and volunteer, in addition to consistent thoughts about the child's future, appears to be the basis of successful home-based programmes. However, without structured support by the Rehabilitation Technicians, this will be haphazard and difficult o replicate to other situations.

Returning to the fourth research question of this thesis in light of the problems experienced with the follow-up of people with disabilities, it must be concluded that the Rehabilitation Technicians have not been able to adequately fulfil their role in the CBR process. In progress and evaluation meetings, Rehabilitation Technicians have repeatedly pointed to three major problems encountered during these projects:

– Shortage of manpower
  The Rehabilitation Technicians reported that one Rehabilitation Technician is fully committed by the responsibilities of the CBR project. With two or three Rehabilitation Technicians in a district, the other(s) will be needed to provide rehabilitation in the district hospital, participate in workshops, or join outreach services
– Unreliable transport
  The Rehabilitation Technicians had to rely on transport for other outreach services in order to reach the project areas. A few Rehabilitation Technicians were able to use motorcycles for follow-up visits, but even they were restricted in mileage.
– Inadequate communication
  Communication with the people with disabilities participating in the programme, volunteers, rural clinics, and referral centres was problematic during these projects. Postal services were unreliable in the rural areas, and the telephone system did not cover large portions of the rural areas. Quite often communication breakdowns were caused by the Rehabilitation Technicians failing to find transport in order to reach pre-arranged meeting points.

These problems, and possible solutions, come with a specific idea about the role of the Rehabilitation Technicians in the CBR projects. In the CBR pilot projects, the Rehabilitation Technicians wanted to carry out, or at least supervise, the training of every person with a disability. Volunteers and caregivers were given the merely instrumental role of continuing the instructions given by the Rehabilitation Technicians. This approach is not much different from the one used in the hospitals where the Rehabilitation Technicians use their clinical skills in treating patients. However, for the Rehabilitation Technician to function effectively, families and communities should be given a larger role in the rehabilitation of people with disabilities. This would require professionals to cooperate and share their skills with lay people, and it their work should focus on problems encountered in daily life in addition to the help available from families and communities instead of on medical diagnosis and scientific treatment plans and techniques.

These CBR projects have demonstrated more diverse needs for rehabilitation than are found in the hospital-based situation. In CBR projects people with cognitive, affective, and sensory disorders make up the principal group of people with disabilities. The Rehabilitation Technicians were not confident about setting up training programmes for such a variety of people with disabilities (including people with mental handicaps, communication difficulties, visual problems, or mental disorders) as these types of conditions were encountered less frequently in the rehabilitation departments of the hospitals in which the Rehabilitation Technicians were based. This resulted in a high proportion of people with disabilities being referred to a hospital or specialized service.

It proved very difficult to keep the volunteers motivated for a period longer than the initiating phase of the project (the first four weeks). Many dropped out and most of the others have asked for incentives, formal training, etc. Furthermore, the volunteers were not clear about their role in the projects. Since the Rehabilitation Technicians intended to visit the people with disabilities themselves, the volunteers felt there was not much left for them to do.

Two years since the beginning of the CBR projects, no more than one third of the volunteers are still active. The Rehabilitation Technicians have not been able to establish the exact reasons for this significant loss of volunteers but they have suggested that it might have been due to:

- Lack of incentives: volunteers were expecting some kind of incentives for their services,
- Transport: it was very time-consuming to visit homes that were often miles away from each other,
- Unreliable communication: the volunteer was often unaware of the visits made by the Rehabilitation Technician to the project area,
- Overloading: the people who volunteered were often involved in a number of other projects run by the government or NGOs,
- Declining motivation: rehabilitation is a long term process which often lacks direct results and it is often challenging to maintain motivation on the long term,
- Lack of job perspectives: some people were hoping to find a job through this voluntary work, and, when it became clear that there were no jobs available they quit.

Village Community Workers appeared to be the most stable group of volunteers. The reason for this was most likely that they were part of a well functioning structure, they met on a regular basis, and they were employed by the government. The regular meetings of the Village Community Workers provided an opportunity to meet with the Rehabilitation Technicians. The organisation of the Red Cross volunteers wasn't strong enough in the project areas to allow structured meetings with the Rehabilitation Technicians.

The Village Community Workers were involved in a number of community projects (e.g. irrigation, women's affairs) and the Rehabilitation Technicians were initially concerned that no time would be left for their CBR duties. However, the Rehabilitation Technicians reported that most of the Village Community Workers who are still involved are motivated to carry on with the project. In the implementation phase, a total of 1614 people with disabilities were included in the CBR projects. This implies that, if every volunteer stayed involved, one volunteer would support three people with disabilities. Due to the high drop out of the volunteers, this has now increased to one volunteer for nine or ten people with disabilities. Given the distances and the other obligations of the volunteers, it is unrealistic to expect the volunteer to visit more than three people with disabilities on a regular basis.

If the volunteers are indeed to be seen as part of the solution to the manpower, transport, and communication problems, a plan should be made to keep them involved. Such a plan should include regular workshops, educational materials for and to be used by the volunteers, assistance for transport, and visits accompanied by the Rehabilitation Technician who can discuss the progress of the training and provide feedback on it. Volunteers have not been paid extra for their CBR work, and, given the government policy and structure in Zimbabwe, this does not seem possible. NGOs running similar programmes have resorted to paying the volunteers, and they sometimes used a bonus system to keep the volunteers motivated.

It can be concluded that implanting CBR in decentralised rehabilitation services has definite advantages with regards to the availability of an intermediate rehabilitation cadre, the Rehabilitation Technicians, and an accessible referral system. However, this has at the same time, proven to be the 'Achilles heel' of the projects. Rehabilitation Technicians, volunteers, and caregivers were trying to fulfil their roles within that system, with the Rehabilitation Technician as the most peripheral rehabilitation worker. Guidance and control of the projects stayed within the system and with the Rehabilitation Techinician. Volunteers and caregivers were willing to get involved, but the instrumental role they were given, in combination with unsatisfactory communication with the RT, led to diminishing enthusiasm for the project. Rehabilitation Technicians became frustrated because they could not meet their own expectations in addition to those of the volunteers and caregivers. Given the high drop out rates of volunteers and the low, and even further decreasing, number of follow-up visits, the CBR pilot projects in Zimbabwe were easily at risk of fading out.

Several suggestions for making these CBR pilot projects more viable have been provided:

- Divert the control of CBR projects from the Rehabilitation Technicians to groups in the community. In some projects 'CBR committees' were formed. With her specific knowledge, the Rehabilitation Technician can be an important resource person for such a group. There is no necessity that one group cover the needs of all people with disabilities. These needs might be very different. Different groups of people will emerge and make points specific to their own needs. These groups can be based on a common impairment (e.g. people with vision disorders) or on a common interest (e.g. access to a credit scheme).
- Make the interests of people with disabilities and their caregivers part of programmes running in the community. In fact, a 'disability check' can be done on every programme to make sure that people with disabilities can participate and benefit from these programmes. Rehabilitation Technicians can facilitate and support a small group of people who will be the eyes and ears of the people with disabilities. In addition, they can sensitise policy makers and programme implementers regarding the accessibility of programmes for people with disabilities. Naturally, such a group will include people with disabilities themselves.
- Networking is a powerful tool, even in rural areas. One of the main problems of the described CBR projects is that it is a more or less hierarchical programme within one Ministry. With the Rehabilitation Technicians as an intermediate cadre, the vertical communication (within the health system) is well covered. Improved horizontal communication (for example, between local authorities, teachers, social welfare officers, businessmen, and traditional healers at the community level, will increase the viability of CBR projects. It has been observed that Rehabilitation Technicians consider themselves personally responsible for the training of the person with a disability. Instead, the Rehabilitation Technician should assist in generalising the needs of people with disabilities and aid in transforming these into opportunities that can be created at the community level by the people living in the community.
- Accept differences and avoid a dogmatic approach as opportunities and solutions will differ per community. For example, an initiative to integrate children with a mental handicap in the mainstream classroom might not always get support from the teachers. A special class in the same school might be acceptable for both the caregivers and the teachers. Also examples of

communities setting up local homes for severely disabled children in which parents take turns caring for these children have been seen. These types of initiatives are easily dismissed as not CBR, but, instead of judging and dismissing these situations too quickly the Rehabilitation Technician and the other people involved could use these initiatives to train groups of parents, to aid in developing the quality of care, and, finally, to progress these homes to towards complete resource centres within the community.

The CBR pilot projects in Zimbabwe have shown that Rehabilitation Technicians are indeed the backbone of the CBR projects. However, given experiences in the eight pilot projects, it is argued that their role in the CBR process needs to be revised. The stability of the project needs to be grounded in community structures. The Rehabilitation Technicians can improve their effectiveness by adjusting their role to a position in which they serve as resource people for permanent or temporary community groups of people involved with the integration of people with disabilities. Although this does not resolve the practical problems they have experienced so far, it is expected that the CBR project, and the individual functioning of the Rehabilitation Technicians, will be less affected by these problems as community contacts will be more concentrated and better organised.

7

Appreciation of Community-based rehabilitation by caregivers of children with a disability

This chapter is a revised version of the article by H.J.M. Finkenflügel, V. van Maanen, W. Schut, A. Vermeer, J. Jelsma, A. Moyo, published in Disability and Rehabilitation (1996), Volume 18, number 5, page 255-260.

Abstract

Evaluations of Community-based rehabilitation (CBR) programmes generally focus on quantitative data. To gain insight into the determinants of the outcomes, process oriented data are needed. In this chapter, a study to assess the appreciation of Community-based rehabilitation by caregivers of children with a disability is presented. Six variables that possibly correlate with the evaluation of CBR by caregivers of children with a disability have been identified from the literature. These variables are (1) traditional beliefs, (2) impact of a child with a disability on the caregiver, (3) community involvement, (4) the perceived ability to teach the child, (5) attitude towards various health services, and (6) expectations for the future of a disabled child.

The study was done in the CBR projects in Zimbabwe. Seventy-five caregivers were interviewed. The background, perceived abilities to teach, and expectations of the caregivers were very different. The findings of this study suggest that a positive appreciation of CBR is related to a negative attitude towards various health services, and that a positive perception of the ability to teach the child is related to more positive expectations for the future of the child.

7.1 Introduction

After Independence in 1980, Zimbabwe expanded and decentralised its health care system (Ministry of Health Zimbabwe, 1990b). In line with this overall development, rehabilitation services have become available in the main hospitals, provincial hospitals, and district hospitals. To meet the demands of people with disabilities at the community level, the government introduced Community-based rehabilitation (CBR) (WHO, 1982). A report (Ministry of Health Zimbabwe, 1990a) and an evaluation study (Njini et al., 1991) presented extensive sets of data on the number of clients identified, the number of clients who received assistance, the type of assistance offered, etc. Little information was provided about the process of implementing CBR and the appreciation of CBR by caregivers and people with disabilities. This study was interested in the level of appreciation of CBR held by caregivers of children with a disability in addition to the underlying factors that could be of importance in the appreciation of CBR. O'Toole (1988) emphasised the importance of balancing quantitative gains with a qualitative analysis of the process involved. It is, however, not clearly determined what variables should be considered when carrying out a qualitative evaluation. Six potential influencing variables were identified in the literature. These are discussed briefly hereafter.

– *Traditional beliefs about children with disabilities.*
  Several authors point at the possible significance of traditional beliefs regarding causes of disability when dealing with children with disability. O'Toole (1988) found that, during CBR projects, important changes occured in the attitude of the caregivers towards the children and towards themselves. However, Jackson and Mupedziswa (1988) concluded that the CBR programme, whilst valued for its practical assistance, had almost no impact on people's beliefs about causal agents. Introducing rehabilitation services into a community may interfere with culturally related beliefs about disability.
– *Impact of a child with a disability on the caregiver.*
  Within traditional medicine, the primary concern is why a disability has arisen (Devlieger, 1989a). The search for an explanation concentrates on the subjective experience and on the

explanations given for it within the framework of culture and religion. A child with a disability can be seen as a sign that there is something wrong with the family (i.e. the mother). Also, a child with a disability cannot fully take part in daily household and economic activities. As a result, having a child with a disability can place an economic burden on the family and, as such, may cause 'handicapped' families (Burck, 1989).

– *Community involvement.*
  When introducing rehabilitation based on parental and community involvement, it is hoped that the caregiver will experience relief through improvements in the abilities of the child and through moral support. Thorburn (1990) stated that overwork, poverty, severe social tension, and sheer exhaustion make involvement in rehabilitation very demanding for the parent. One of the basic assumptions of family -and community- involvement is that the caregiver gets full support from the family and the community. According to Miles (1985), *"the great bulk of care, treatment, therapy and rehabilitation of persons with a disability has always been given, is still given and -for the foreseeable future- will continue to be given by parents, relatives, neighbours, traditional practitioners and disabled people themselves"*.
  Unfortunately, when one looks more closely into the way a community works, it appears in reality that communities are often divided, stratified societies. Also, according to O'Toole, for 'community' we could read 'family', and for 'family' 'mothers' (1987). These observations question the idea of community involvement and the possibilities for creating and sustaining it.
– *The caregiver's perceived ability to teach the child.*
  Jaekle (1986) made clear that while most parents want to help their child with a disability, they often do not know how to proceed. O'Toole (1989) mentioned three prerequisite skills, on the part of the mothers, to implement a parent involvement programme: (1) an understanding of child development, (2) a belief in teaching, and (3) opportunities for teaching.
– *Attitudes towards various health services.*
  Zimbabwe has set up a decentralised health care system, including district hospitals, clinics, and rural health centres. The traditional healer is also a well known phenomenon in Zimbabwe. Caregivers of children with a disability appear to seek help from different health services. Satisfaction with the services available might influence the acceptation and appreciation of CBR by these caregivers.
– *Expectations for the future of a disabled child.*
  The future prospects of the child with a disability might be closely related to parental evaluation of the services provided. If no progress is perceived by the caregiver early on in the treatment, future prospects can soon become dimmed. In particular, the perceived cultural importance of being able to contribute to the family, to marry, and to raise a family must be noted (Devlieger, 1989a).

7.2 The aim of the study

The aim of the study was to explore whether any of the six variables listed above had an influence on the appreciation of Community-based rehabilitation by the caregivers of a child with a disability. Also, special interest was directed at the relationships between the variables

identified. These included, for example, the relationship between traditional beliefs and the impact of a child with a disability on the caregiver, the relationship between traditional beliefs and attitude towards health services, and the relationship between community involvement and the impact of a child with a disability on the caregiver.

7.3 Method

The study was conducted in four districts in Zimbabwe, and it was carried out between April and October 1991.

A questionnaire, covering the six variables, was constructed. Each variable was represented by one or more questions. For those respondents that were involved in CBR, the question 'Are you satisfied with CBR?' was added. This questionnaire was pilot-tested in the Seke district which was the site of one of the eight CBR projects in Zimbabwe. The questionnaire was translated into Shona, one of the indigenous languages. However, interpreters pointed out many local differences in the Shona translation, and, as a result, they preferred to use the original questionnaire in English (see Appendix). The researchers took extensive notes during the interviews. These notes were discussed with the respondents. The interpreter played an important role in obtaining clarification where necessary.

The respondents in this study were the primary caregivers (usually the mother but sometimes a grandmother, aunt or elder sister) of a 5-14 years old child. In selecting the caregivers of children with a disability, we limited the study to children referred to as having 'neurological disorders' (Ministry of Health Zimbabwe, 1990a). Three different groups of caregivers, with potentially contrasting views, were interviewed:

Group A:

– Caregivers of children (age 5-14) with a disability participating in a CBR project and having had at least three follow-up visits since the start of the projects.

Group B:

– Caregivers of children (age 5-14) with a disability identified in an early phase of a CBR project but having had no contact with rehabilitation services since that time.

Group C:

– Caregivers of children with no disability and living near families with a child with a disability.

Throughout the four districts, a total number of 1060 people in need of rehabilitation were identified; 287 (27%) were children in the age group 5-14. Of these children, 90 were classified

Table 7.1 Characteristics of the children with a disability being cared for by the respondents (n=50)

	Sex		Age (mean)	Total number of children in the family	Type of neurological disorder		
	Female	Male			Cerebral palsy	Polio	Other
Group A	13	12	9.0	4.3	17	3	5
Group B	10	15	8.9	6.0	19	3	3

as having a neurological disorder. In every district these children were placed on a randomised list. The records for these children were studied starting from number one, and the rehabilitation worker responsible for the child was often asked to provide additional information. The children were then assigned to group A (at least three follow-up visits), group B (no follow-up visits), or put aside (one or two follow-up visits or uncompleted records) as was appropriate (table 7.1, page 147).
There was a weighted district representation in all three groups. Each group consisted of 25 respondents. The respondents were visited at their homes, regardless of how far the interviewers had to travel. Only a few respondents were not found at their homes. In these cases, the next respondent on the list was taken instead.
Responses to the different questions have been tabulated using EpiInfo and SPSS 11.0.

Table 7.2 Number of respondents per group for each variable (n=75)

	Frequency				Chi-square		
	Group A	Group B	Group C	**Total**	A-B	A-C	B-C
1 Traditional beliefs about children with disabilities							
Cultural	12	8	6	**26**	.75	2.17	.09
Not cultural	13	17	19	**49**			
2 Impact of a child with a disability on the caregiver							
High	14	12	N.A.	**26**	.08	N.A.	N.A.
Low	11	13		**24**			
3 Community involvement							
High	18	21	19	**58**	.47	.00	.13
Low	7	4	6	**17**			
4 The caregiver's perceived ability to teach the child							
Able	12	11	13	**36**	.00	.00	.08
Not able	13	14	12	**39**			
5 Attitude towards various health services							
Positive	12	13	N.A.	**25**	.00	N.A.	N.A.
Negative	13	12		**25**			
6 Expectations for the future of a disabled child							
High	14	17	4	**35**	.34	6.82 *	11.82 *
Low	11	8	21	**40**			

* $p \leq 0.01$, N.A. = not applicable

Additionally, contingency tables were drawn by cross-tabulating the question 'Are you satisfied with CBR?' with the six variables. For variables 2, 3, 5, and 6 a procedure was designed to distinguish between a high and a low score (or a positive and negative one). The total scores of all the respondents were used as a reference for the individual scores. To make this possible, every question (3, 5, or 6 per variable) was rated either 0 or 1. An individual score for each variable was calculated. For every variable, the scores of all respondents were pooled together and the mean for each variable was calculated. This mean was used as the cut-off point to distinguish between a high and a low score for these variables. In order to compare these constructed scores between the three groups and to relate variables within a group, a (corrected) Chi-square test was used.

7.4 Results

In interpreting the findings presented in table 7.2 (and the tables to follow), one should keep in mind that the categorisation is constructed around the means of the total score of the two (for variables 2, 5) or three groups (for variables 1, 3, 4, 6). The figures in the column ('Total') are therefore expected to divide the total of 50 or 75 more or less equally if the scores were nicely balanced.

Table 7.3 Scores related to the question "Are you satisfied with CBR?" (Group A: n=25)

		Satisfied with CBR		
		No	Yes	Total
1 Traditional beliefs about children with disabilities	Cultural	4	8	12
	Not cultural	3	10	13
2 Impact of a child with a disability on the caregiver	High	4	10	14
	Low	3	8	11
3 Community involvement	High	6	12	18
	Low	1	6	7
4 The caregiver's perceived ability to teach the child	Able	3	9	12
	Not Able	4	9	13
5 Attitude towards various health services	Positive	6	6	12
	Negative	1	12	13
6 Expectations for the future of a disabled child	High	4	10	14
	Low	3	8	11

Table 7.2 presents scores on the six (constructed) variables for the three groups A, B, and C. With the exception of variable 6, the scores do not show a significant effect. The caregivers' expectations of the child were much higher in group A and group B (all caregivers of a child with a disability) than those in group C (caregivers of children with no disability). In group A, 18 respondents (72%) reported satisfaction with CBR. Scores on the question 'are you satisfied with CBR?' were related to the constructed scores of the six variables mentioned above. These results are presented in table 7.3 (page 149). The number of respondents in group A was too small to allow the calculation of statistically significant relations. The scores on the variables 1, 2, 3, 5, and 6 do not look very different for those who were satisfied with CBR versus those who were dissatisfied. However, a distinctive difference is noted for variable four. This suggests a correlation between a negative attitude towards health services and satisfaction with CBR.
Finally, cross tables for each group were made to correlate with the six variables reciprocally; the result is presented in table 7.4.
Two significant correlations were found in group A. It was shown that a belief in 'cultural causes' was related to a low impact of a child with a disability on the caregiver. It is also

Table 7.4 Correlations between the six variables for groups A, B, and C (chi-square)

	1	2	3	4	5
1 Traditional beliefs about children with disabilities					
2 Impact of a child with a disability on the caregiver	A 4.81 * B 3.44 * C –				
3 Community involvement	A .10 B .71 C .23	A .94 B .01 C –			
4 The caregiver's perceived ability to teach the child	A .04 B .20 C .68	A .34 B .05 C –	A 1.47 B 1.86 C .01		
5 Attitude towards various health services	A .99 B .99 C –	A .34 B .37 C –	A .10 B 1.01 C –	A 1.99 B 1.07 C –	
6 Expectations for the future of a disabled child	A 1.07 B .16 C 1.77	A 2.23 B .99 C –	A .68 B 2.24 C .00	A 7.00 * B .20 C .00	A .34 B 2.49 C –

* $p \leq 0.1$

interesting to note that a high score on 'the caregiver's perceived ability to teach the child' was significantly related to positive 'expectations for the future of a disabled child'.
The only significant correlation in group B was between 'cultural causes' and a high 'impact of a child with a disability on the caregiver', and no significant correlations were found in group C.

7.5 Discussion and conclusions

Conclusions concerning the appreciation of CBR by caregivers of children with disabilities should be approached very cautiously considering the explorative nature of this study in addition to the limited sample size of the three groups.
From the results, it appears that a lack of satisfaction with the other various health services available might be related to a positive evaluation of CBR. This can be perceived as a positive sign regarding the efforts CBR is trying to make. Apparently, when existing services do not meet the expectations of the caregivers, CBR appears to be a welcome alternative. Travelling with a disabled child is especially difficult in rural areas. This could be a strong reason for not using the services offered in hospitals and clinics or for non-compliance with the therapy. An essential difference between the existing health services and CBR is that CBR takes place in the people's homes.
No other variable could be related to a positive or negative appreciation of the project. One might have expected that high future expectations would be related to a positive evaluation or that a strong cultural belief was related to a negative evaluation of the project. In relating the variables reciprocally, no support was found for the idea that caregivers would be more negative towards health services when they considered the cause of the disability of their child to be related to cultural influences. Also, no relation of these traditional beliefs was found with the evaluation of CBR. The interference of traditional beliefs concerning the disability of the child indicates that contradictory results might have been obtained. While belief in a cultural cause was related to a lower 'impact of having a disabled child' in group A on the other hand it was related to a higher impact in group B.
No support was found for the idea that a high community involvement would result in a low impact of a child with a disability on the caregiver. This might indicate that, from the perspective of the caregiver, the effectiveness of community involvement in rehabilitation is low.
The results showed that a perceived ability to teach the child was related to higher future expectations for the child. Therefore reinforcing and increasing the caregiver's ability to teach the child should be a main objective in CBR. This implies a change in the role of rehabilitation staff, specifically from treatment to teaching and from convincing to discussing.
This study focused on six variables that were obtained from the literature. Other qualitative aspects might also influence the appreciation of CBR by the caregiver. For example, the perceived ability to teach the child might be related to the severity of the child's disability.
Rehabilitation workers, community leaders, local supervisors, and caregivers can have very different expectations for the CBR programme. When we asked the caregivers what kind of

help they needed, two-thirds of the caregivers answered that they needed material and financial assistance. In some cases, caregivers and community leaders became discouraged when it became clear that the CBR programme would not solve these problems. Therefore, the preset ideas and expectations that people have regarding a programme can also be of importance for the appreciation of the outcome of the programme.

The complexity and possible inconsistency of the relations between variables may be characteristic for something as many-sided as the circumstances encountered by the of primary caregivers of children with a disability. In this study we were impressed by the many differences observed between the caregivers. These included differences in the attention and care given to the disabled child, differences in the support provided by their families and communities, differences in the perceived future prospects for the disabled child, and differences in expectations of the CBR programme.

One shortcoming of this study was that the researchers had to work with local interpreters. The validity of the answers given were restricted by their ability to translate and their ability to relate to the caregivers. Also, since there were different interpreters working in each area, it was difficult to compare the answers, and the subsequent scores between the different areas.

There is also the danger of respondent bias, particularly because Dutch students carried out the interviews by travelling around on foot and visiting people in their homes. This situation may have led respondents to give answers they thought we would like to hear. Nevertheless, due to the length of the interviews (about 45 minutes) and the routine established in approaching people, it was felt that the respondents were generally very open and gave unbiased answers.

Calculating overall scores for the six variables proved to be difficult. Respondents did not always answer with a simple 'yes' or 'no'. The extensive notes on the structured interviews were analysed by the researchers, who, after discussion with the interpreter, often reached a consensus on the scores. Some answers proved to be too open or too ambiguous to simplify to a yes or no answer.

CBR is not just a different way of organising rehabilitation services. It is a type of rehabilitation whereby caregivers are very much involved with, and even made responsible for, the rehabilitation process of their child. Instant results (e.g. decreasing a contracture, providing a sitting aid) can be impressive, but they will not endure if they are not an integral part of a rehabilitation process that considers the background, perceived abilities, and expectations of the caregivers. In order to be able to fully account for these aspects, qualitative research in CBR needs to be further developed.

Appendix: Questionnaire used to evaluate the appreciation of CBR by the caregivers of children with a disability

1 Traditional beliefs about children with disabilities	1.1 What is, in your opinion, the cause of the disability?
2 Impact of a child with a disability on the caregiver	2.1 Does your partner blame you for giving birth to this child? 2.2 Do you feel less respected by your family because you have a child with a disability? 2.3 Do you feel less respected by people in the community because you have a child with a disability? 2.4 Does your child need help in daily living? 2.5 Is the child helping you in the household, doing work in the field etc.?
3 Community involvement	3.1 Does your partner help in taking care of the child? 3.2 Does your family help in taking care of the child? 3.3 Is someone from your community helping?
4 The caregiver's perceived ability to teach the child	4.1 Do you feel able to teach your child things?
5 Attitude towards various health services	5.1 Did you go for help to the village community worker? 5.2 Did you go for help to the n'anga (traditional healer)? 5.3 Did you go for help to the hospital or clinic? 5.4 Were you satisfied with the help you got from the village community worker? 5.5 Were you satisfied with the help you got from the n'anga? 5.6 Were you satisfied with the help you got from the hospital or clinic?
6 Expectations for the future of a disabled child.	6.1 Do you think the disability will lessen? 6.2 Will you need help in the future? 6.3 Do you think you can keep the child at home? 6.4 Do you prefer the child to go to an institution? 6.5 Does your child go to school? / Would you like your child to go to school? 6.6 Do you think your child will be able to live on her or his own, earn a living, get married?
For group A only	"Are you satisfied with CBR?"

8 Stakeholders' influences in four CBR scenarios

Abstract

This chapter recapitulates the research questions formulated in chapter 1. The premise of this thesis is that the CBR process can only be understood through the stakeholders involved. The adequacy of the interventions is largely determined by the competencies of the stakeholders and how they relate with one another. In the previous chapters, it has been concluded that CBR is not only grafted on clinical services but it also follows the same pyramidal structure, characterised by a strong emphasis on the knowledge and skills of professional rehabilitation workers. In CBR projects the Intermediate Level Supervisors and the lay stakeholders were very much an extension of this professional cadre. This implies that the influence of these stakeholders is more or less on loan from the next stakeholder in the hierarchy, and this influence is therefore regulated by the structure of the project. In fact, stakeholders are hardly able to make decisions that affect their own position in the process, or the direction, of CBR.
'Conflict of interests' between the different stakeholders have influenced the discussion and development of CBR. One 'conflicts of interest' regards the inclusion of people with similar or different disabilities in a project (selective versus comprehensive), and another addresses whether interventions should focus on the individual within her community or within on the society. As a result, the perception of the required competency-levels of the stakeholders involved will differ. These 'conflict of interests' have been adopted into four possible scenarios in CBR. A realistic understanding of the competency-levels of the different stakeholders in each scenario will aid in empowering these stakeholders. As a result, they will be able to influence their own position and thus make a difference in the overall process. Finally, future research should focus on the influence of the stakeholders involved in CBR. This will not only help to understand how the different stakeholders perceive, fulfil, and shape their role in part of the process it will also reveal their needs for information, resources, training, and support and thus guide the direction of the entire CBR process.

8.1 Introduction

In order to explain 'state of the art' aspects of CBR, a colourful palette is needed to express its many differences. CBR projects exist in different parts of the world, have different objectives, and involve different people. This diversity is appreciated since it allows the CBR process to be a tailored to the needs of people with disabilities in specific circumstances. However, the downside of this diversity is that knowledge and experience gained in one project is not easily shared with others. Making generalisations between projects and building CBR theory also becomes difficult as a result of these differences. Consequently, the relevance and impact of CBR is still being discussed, even after twenty-five years of experience with the concept. Ten years after the introduction of the CBR concept Momm & König (1989), commented that *"Rarely in the history of services for disabled people has an idea attracted so much unqualified support as has "community-based rehabilitation"*. In 2002, Wirz & Thomas (2002) stated that: *"the field is criticized as having poor indicators with which to measure success"*. It is indeed disconcerting to see the development of CBR going from 'unqualified support' to 'poor indicators to measure success'. This can hardly be seen as progress, and it should be questioned whether or not these quotes reflect the maturing of CBR adequately. Therefore, in this thesis the main research question was:

> *What, so far, is the knowledge and evidence base for CBR, and to what extent can an analysis of the roles, interests, and powers of the different stakeholders involved add to the body of knowledge and further development of CBR?*

This main research question was divided into four research questions, and these have been discussed in this thesis. In this chapter, the answers to these questions are summarised and positioned in a wider discussion on the potential and future directions of CBR and research within CBR.

8.2 Knowledge and evidence base for CBR

In the past 25 years many rehabilitation workers and researchers have entered the discourse on the relevance and effectiveness of CBR. Day-to-day discussions about CBR will probably, and hopefully, take place between different stakeholders in the community, primary and secondary schools, training centres, rural and district hospitals, training schools for rehabilitation workers, and in the offices of those responsible for implementing CBR programs. However, there is a need for discussions and research that extends beyond particular projects and provides a broader perspective on CBR. The theoretical framework of CBR (see above) should be substantiated with knowledge and evidence for CBR. From the beginning, researchers that were often personally involved in implementing CBR projects have stressed the need for sharing information between projects and carrying out research to account for the efforts made and the results achieved in these projects. This call for the importance of research has been increasingly expressed and is very dominant in the current discussion on CBR. In fact, some argue that the whole concept will disappear if the people involved in CBR cannot provide evidence for the effectiveness of CBR (Thomas, 2002). In their view, evidence is needed to convince policy makers, donor agencies, training centres, and other (non) governmental organisations of the relevance and effectiveness of CBR in dealing with the needs of people with disabilities. They also believe that supportive evidence for CBR is required in order for the needs of people with disabilities to compete with other health and socio-economic issues that need to be addressed.
It is important to discuss whether the apparent lack of evidence on CBR is indeed the reason for the perceived diminishing interest in CBR. It is likely that the lack of evidence plays a key role in the possible decrease in attention directed to CBR, but it is important to remember that other factors will play a role as well. In order to begin a constructive discussion on this issue, it is most important to establish what the knowledge and evidence base for CBR actually is. Therefore, the following research question was formulated:

> *Do research studies provide evidence that CBR is a relevant and effective alternative for rehabilitation of people with disabilities in developing countries?*

In order to address this question, an extensive literature review was carried out and 128 articles were identified that met the criteria set. Only ten of the studies were classified as intervention studies. However, nine of these studies suffered from an absence of (defendable) before-after measurements or control groups and their contribution to the evidence base for CBR is therefore limited. Of the 128 articles, 85% are of an explorative nature and illustrate an aspiration to discuss CBR extensively. This might be indicative of the fluidity of the CBR programme and the underlying concepts. These studies could be interpreted as an attempt to anchor CBR to concrete situations (case reports), to other variables (descriptive studies), or to processes and developments in disability issues, communities, or organisations (theory papers). Clarification of the relevant concepts is indispensable in research studies. However, findings from case reports and descriptive studies cannot easily be generalised since the circumstances of the projects will differ, and no common, and comparable, methodology has

been used between the projects. In summary, the evidence base for CBR is fragmented and incoherent, and there is no substantial evidence demonstrating that CBR is indeed a relevant and effective alternative for rehabilitation of people with disabilities in developing countries. However, on the basis of this literature review, it also cannot be concluded that CBR is therefore an ineffective concept. One of the difficulties encountered while making conclusions either way is that the relevance and effectiveness of other types of rehabilitation in developing countries (e.g. institution based rehabilitation) has also not been established, and therefore a comparison between different types of rehabilitation cannot be made easily (although a first attempt was made by Evans et al. (2001)). The emerging problem is that no consistent theoretical framework is being used. In situations and studies where relations between input and expected outcomes are not made explicit and the process itself remains undefined, any research outcome is unfocussed, or, to paraphrase Miles (1994a), like shooting three elephants on a bicycle with one shot of hail.

8.3 A programme theory for CBR

The early expectations for CBR were straightforward. By organising rehabilitation in a different manner (i.e. by involving lay people and an additional professional cadre), not only could more people with disabilities be assisted, but the assistance offered would meet their needs more effectively. From the start, CBR has been a practical approach based on easy-to-understand assumptions and using simplified, or demystified, interventions in the rehabilitation of people with disabilities. In its early stage, the theory of CBR was simple and basically presented ideas more than explained facts, events, and relationships. The inherent disadvantage and danger of this lack of theory building in its CBR's early stage was that the rightfulness and effectiveness of the interventions could not be established or challenged. In fact, in situations where the input, intervention processes, and outcomes were not made explicit, rehabilitation workers and researchers had to resort to a belief in CBR instead of relying on assessments of the processes and benefits of it. This observation and concern resulted in the first research question of this thesis:

> *Can a programme theory for CBR be identified or constructed, and how can this theory function as a framework for designing interventions, evaluating the process, and strengthening the roles of the stakeholders involved?*

This question has been addressed specifically in chapter 3. It was concluded that theory building for CBR has been weak. This statement clearly applies to the first ten to fifteen years, and it, in fact still pertains to the current 'state of the art' of aspect of CBR. Different models for CBR have emerged and some rehabilitation workers have branched away from CBR and developed their own approach using a different terminology. Also, in the 25 years that the concept of CBR has been promoted, used, and criticised, a noticeable shift from an individual approach emphasising the functional progress of the person with a disability (often perceived similar to a medical model and), to a community model (emphasising participation and

integration in the community) to a social or human rights approach has occurred. This shift has altered the involvement and influence of the stakeholders involved and the ownership of CBR programmes has been disputed. It is tempting to develop different theories to satisfy different views or to see the different concepts as developmental stages within a generic concept of CBR. Both approaches are not satisfying and in fact not necessary to address the difficulties of the inconsistent and obstructed theory building that is encountered with CBR. Although a programme theory for CBR has not yet been developed, it is possible to create one on the basis of the ideas presented in the available literature (see figure 3.3. page 67). The six principal stakeholders in CBR form the heart of the model. They are positioned in a roof-tile construction and together cover the community, district, and national level. The inputs and potential outcomes at each stakeholder level are described. The basic idea in this model is that all stakeholders, with the exception of people with disabilities, create an input for the next level, and as such, are part of the intervening process. Since the desired outcomes will differ, the strategies used to achieve these outcomes will vary. The strategies used to train a person with a visual disability to find her way around the house will differ from the ones used to create an awareness of the needs of people with disabilities in a community. The strategies will also differ from those used while lobbying to legalise affirmative action to ensure that every company accepts a certain minimum percentage of people with disabilities into its work force. All of these interventions will require different strategies. Due to the complexity of the CBR it is unlikely that there will be one dominant strategy or that all the possible strategies will be listed. The development of the CBR concept by nature requires an eclectic and inter-disciplinary approach that incorporates strategies developed in such fields as medicine, educational psychology, education, sociology, etc. The model presented here is believed to provide coherency and does not claim uniformity. In order to address a problem or to obtain a desired outcome, the appropriate stakeholder level in the intervention process must first be identified, and decisions must be made regarding the appropriated inputs and strategies to employ. Although this model might be perceived as complex, it is important to realise that research will generally focus on either one intervention level or the relations between adjacent stakeholders and the environment (e.g. institutional services, related programmes), and thus will employ only part of the model.

The final answer to the first research question is ambiguous. A full programme theory for CBR that explains facts and events cannot be identified. In fact, the intervention processes are often not obvious, and the inputs and outcomes of programmes are linked without questioning first the appropriateness and effectiveness of the intervention, and second other possible intervention strategies. However, despite the differences in the CBR approaches employed by various rehabilitation workers and researchers it was still possible to construct a generic model to understand and further explore processes within CBR, specifically regarding the role of the principal stakeholders involved. This model can serve as a framework for further theory building

8.4 Competency-level of stakeholders

CBR can be characterised by the different levels of intervention that correspond to the six principal stakeholders that possess a defined interest in the programme in addition to the ability to influence the programme. The third research question posed in this thesis was:

> *Which stakeholders are relevant in CBR, how do they play a role in the rehabilitation process, and how can they be empowered?*

A normative description of the competency-levels and decision-making capabilities of the stakeholders is presented in chapter 4. CBR relies to a large extent on the involvement of family trainers, volunteers (Local Supervisors/Facilitators), and generic rehabilitation workers (Intermediate Level Supervisors or Rehabilitation Assistants/Technicians). Although family trainers and volunteers have probably always been involved in some (informal) way to assist a person with a disability who needs help, in CBR their involvement is expected to be more structured and they are positioned within a formalized hierarchy of rehabilitation services. Family trainers are trained to carry out daily remedial routines with the person with a disability and to support this person while they are participating in community activities. Volunteers live and work in the community, are not entitled to a salary, and have no formal training in rehabilitation. Instead they are educated in workshops and 'on-the-job'. The Intermediate Level Supervisors are (semi) professionals with 1-2 years of training, who work at the district and community level and are, in general, based in one of the main centres in the district. Inserting and formalising these stakeholders in the rehabilitation process has had consequences for the roles of the therapists and trainers. Instead of providing hands-on therapy or training and working directly with the people with disabilities (as they were educated to do), they are more and more involved with the education and supervision of the Intermediate Level Supervisors and with the managerial aspects of the programme. They now only see people with disabilities when they are referred to them for assessment or specialised training. Thus their intervention should aim towards instructing and strengthening the Intermediate Level Supervisor so that she is able to implement her own intervention. Specialists and planners, the sixth and last principal stakeholders, do, as in institution-based services, see people with complicated impairments and will be involved in planning, monitoring, and evaluating rehabilitation services. The planners will also have to report to governments and (donor)organisations, and they will be held accountable for the inputs and outcomes of the project. Although their role might not appear to be much different from a role in institution-based services, services in CBR are not as visible and are therefore more difficult to manage. CBR projects, possess the same pyramidal structure with the same 'chain of commands' as IBR, but more levels are involved and the distances, both structural and physical, between the head offices and the rehabilitation workers have increased. This increased distance goes hand in hand with a loss of direct control over the different levels. Due to this distance and the resulting loss of direct control, an 'extended arm' or instrumental approach with delegated responsibilities given by the next level up cannot be managed properly. Also, although CBR workers are positioned in a CBR project structure, they are also part of other structures (e.g. district hospital staff, community health

workers) and will commonly work together with people from different organisations and different educational and professional backgrounds. The emergent invisibility of the interventions at different levels, as well as the lack of control of the diffuse structures and networks in which rehabilitation workers are participating, are apparently innate in CBR.

Additionally, the actual roles of stakeholders in CBR projects in Southern Africa have been assessed and mirrored with the prospected roles in the normative descriptions. In order to gain more in-depth knowledge about the role of stakeholders, studies investigating the functioning of Rehabilitation Technicians and the appreciation expressed by the caregivers of children with disabilities are presented. 'Competence' and 'decision-making' have been adopted taken as concepts central to the discussion of the influences of the different stakeholders in CBR. An understanding of these interwoven concepts is, to a large extent, dependent on the organisational structure of a CBR project. In all of the CBR projects studied, the person with a disability is seen not only as the primary beneficiary of the rehabilitation process but also as someone who is able to define her own needs and influence her own life in a positive way. Generally, the aim of rehabilitation has been defined in terms of the person with a disability gaining independence. Where this might be appropriate terminology for functional activities such as 'dressing herself', 'going to the shops', it is preferable to use 'interdependency' when discussing participating in family and community activities.

CBR is undoubtedly a rehabilitation programme, and therefore the only justification for joining the programme is the possession of a disability. People with disabilities may indeed be disadvantaged, vulnerable, and amongst the poorest in the community, but these conditions alone are not reasons for them to be included in a CBR project. In addition, rehabilitation workers have specific skills and are trained to support people with disabilities. In CBR, the 'reciprocity' at this intervention level is determined by the needs of the person with a disability (as defined by the consequences of the underlying impairment) in addition to the competency-levels of the rehabilitation workers and the family members instructed by the rehabilitation workers.

Not all of the six stakeholders are present or involved to the same extent in every project. In some projects, the therapists or trainers (the third level CBR worker) work directly with volunteers and family trainers, leaving the second level CBR worker out. In other projects, the volunteers were barely involved because the third and second level CBR workers preferred to work directly with the people with disabilities and their families (including family trainers). Although not present in all CBR projects studied, the emphasis on the second level rehabilitation workers, the Intermediate Local Supervisors or the Rehabilitation Technicians, in most of the projects is noticeable. This semi-professional cadre is essentially the backbone of the CBR projects. It is quite surprising to see that these semi-professionals, who, in institution-based rehabilitation, would be dependent on the instructions of therapists, are the key persons in a project, organise their own work, discuss rehabilitation strategies for the district, liaise with other organisations working in the district, train and supervise volunteers, and negotiate with community leaders, teachers, and other influential people in the community.

Looking at the objectives of CBR projects, and the stakeholders responsible for achieving these objectives, it is important to note that the actual roles of the stakeholders differ from the 'normative' positions and competences. The second and third level CBR workers tend to be

responsible for attaining projects objectives. In some cases these CBR workers will even take over at an intervention level that is closer to the person with a disability. The therapists (who in these projects were often expatriates) sometimes worked directly with the volunteers (i.e. in the absence of the Intermediate Local Supervisor) and with the people with disabilities. In fact, by working directly with people with disabilities they were able to do more or less what they were trained to do. However, most CBR projects would assign this stakeholder to a competency-level that focuses on training and monitoring, and does not include regular and direct contact with the person with a disability. With so much emphasis on the Intermediate Local Supervisor, the focus on CBR lays more on the hinge between community and professional services than on the community itself. As with therapists, these semi-professionals (often educated by physiotherapists, occupational therapists, and speech therapists) tend to train the person with a disability directly, and they will occasionally leave instructions for this person and her family. In doing so, the people in the community, (i.e. the Local Supervisors or volunteers), are not given a well-defined and self-directed role in the process. The study carried out in the CBR projects in Zimbabwe showed that two to three years after the start of the project the volunteers were no longer actively involved. Volunteers and Rehabilitation Technicians gave different reasons for this, but the most likely explanation is that volunteers had an instrumental role in the project and were dependent on direct contact with, and instructions from, the Rehabilitation Technicians for their share in the process. This, in addition to communication and transport problems that are inherent to working in rural and remote areas, lead to a limited and infrequent direct contact between rehabilitation workers, volunteers and people with disabilities. As a result, volunteers were dismissed and no follow up of the home based training programmes was provided.

8.5 Stakeholders' influences

The main assumption of this thesis was that understanding and researching CBR could only be done by studying the different levels of intervention and the corresponding stakeholders. Consequently, it has been argued that the position of the will depend on their recognised areas of competence and the influence they can exert within this nexus. Evaluating the anticipated versus the actual influence of the different stakeholders on the rehabilitation process, as presented in this thesis with the 'stakeholders analysis' and by examining 'real life' CBR projects, can be a promising approach to begin the empowering process of the stakeholders involved. According to Randolph (1995), this empowering process takes three steps: (1) share information with clients in a manner that is accessible to clients, (2) create autonomy by developing a clear structure for the relationship, including a vision, goals, and roles that are determined collaboratively, and (3) remove the power hierarchy inherent in relationships through the provision of adequate direction, encouragement, support, skills, and resources. Although his process description best applies to the person with a disability, it can easily be extended to all stakeholders involved in the CBR process. Sharing of information, is an important aspect in CBR. It is important to note that sharing of information is not the same as informing the clients correctly about the training, efforts to be made, expected outcomes,

alternatives, etc. or making information accessible in booklets, manuals, or through the radio or internet. In an empowerment process, the information from the client is the essential piece. Her desires, hopes, ambitions, and fears are a necessary part of the objectives for the training. This not only applies to the level of the person with a disability and the people working directly with her, it also applies to the other levels in the rehabilitation process. Information should be shared between the different stakeholders and, when not available, should be gathered by the stakeholders. While some kinds of information might not be meaningful for one type of stakeholder, it may be the decision-making processes of others. In fact, by presenting CBR as tile-roof model in which stakeholders have their own specialised skills and authority, any stakeholder is can be the end-user of information. Collecting, aggregating, and dispersing information should be an on-going and translucent part of empowering the stakeholders involved in CBR. This brings us to the fourth research question in this thesis:

> *How can knowledge about stakeholders steer the planning, implementation, monitoring and evaluation of CBR projects?*

Although this study revealed a discrepancy between the normative and 'real life' format of CBR, the description of the competence levels and decision-making capabilities of the principal stakeholders appears to adequately cover the CBR process. Not only will this knowledge enhance the process of empowering the different stakeholders, it can also aid in the development of new CBR projects in addition to support existing ones. In the CBR projects studied, the project objectives and the areas of competence of the different stakeholders were far from unambiguous. As was illustrated by studying the functioning of Rehabilitation Technicians in the CBR projects in Zimbabwe, this type of ambiguity can really hamper the development of a CBR project. In these projects, the volunteers were much too dependent on the Rehabilitation Technicians and on the organisation structure of the CBR project. As a result the volunteers became unsure, felt unsupported and dropped out when direct communication between the volunteers and the Rehabilitation Technicians failed. In a complex process with different levels of intervention and support, each level must self-directed and have the ability to act autonomously on agreed objectives. Formulating objectives and assigning these to the different intervention levels should be approached as the central issue in the planning, implementation, and monitoring of CBR projects. The better these objectives are defined, the better they can be linked to the stakeholders, or, to turn it around, the better the competency-levels of the stakeholders are known, the better these objectives can be assigned to them. This is a cyclic process in which the competency-level, decision-making capability, and authority of the stakeholders are defined and matched with the appropriate project objectives. Discrepancies and derailments of this process can be handled in different ways. Too often, more training and increased control are seen as the main methods to improve the process. However, a methodical analysis of the levels of intervention and the mechanisms at each level might expose underlying tensions at these levels (i.e. between the objectives assigned and competency-levels of the adjacent stakeholder). Locating and understanding of these tensions may provide ways in which to adjust the function of this level, and by doing so, the full process. Stakeholders at all intervention levels should have the power to modify project objectives to

match their own skills and to suit the reciprocal relations between herself and the other stakeholders involved. In fact, every stakeholder should ask herself: can I, with my skills and authority, and with the support of other stakeholders, achieve this objective in the time given? Whereas setting the original project objectives will mostly be a top-down process, the modifying of these objectives is a bottom-up process. Monitoring and evaluating the process should thus not only be concerned with the quantitative achievement of objectives. Rather, the modification of these objectives should focus on the reasons why the objectives should be changed, the consequences of these changes for other stakeholders, and the influence of the changes on the whole rehabilitation process. This would result in a demand-driven approach to the whole CBR process. A knowledge of the competency-levels of the stakeholders guides the differentiation and assignment of responsibility for project objectives. At the same time, it is important to acknowledge the unique position of the stakeholders within the family, community, or district and her relations with influential people (e.g. traditional healers, birth attendants, chiefs), local authorities (e.g. councillors, teachers), government staff in Social Welfare, Health Care, etc. These relationships will have a strong influence on the competency-levels of this stakeholder

8.6 Conflict of interests

Working with the competency-levels of stakeholders involved in CBR has proven to be a neat and methodical way to describe the CBR process. However, this does not imply that it is free of arguments. In the 25 years of CBR, 'conflict of interests' between the different stakeholders have influenced discussions about the relevance and cost-effectiveness of CBR, the demystification of rehabilitation, the contributions of lay people, ownership of the projects, etc. These conflicts were often disguised by theoretical and abstract discussions about CBR models. Discussions on models attempt to promote and simplify the CBR process and therefore choose to leave out the potential conflicts between the stakeholders and their perception of their influence in the process. 'Conflicts of interests' regarding three types of issues are discussed hereafter.

Shifting competency-levels

With six principal stakeholders involved in the CBR process it is not surprising that tensions arise between them. Skill and authority will sometimes overlap or be disputed between stakeholder levels. This thesis argues that stakeholders should exert influence to realise and even modify objectives in the project, but this will inevitably change their position in relation to the other stakeholders. As in any hierarchic model, stakeholders will tend to protect their position, and they may attempt to maximise and expand their influence. In the CBR projects in Zimbabwe, the Rehabilitation Technicians had difficulties appreciating the competence of the stakeholders closer to the person with a disability. This resulted in the Rehabilitation Technicians taking over responsibilities at that level, for example, the responsibility for training the person with a disability might be claimed by a professional rehabilitation worker instead of by the family trainer and volunteer. At the same time, stakeholders tend to take over tasks from

the stakeholder above them in the hierarchy, and subsequently end up claiming the position and privileges of these stakeholders. In such situations, standardisation is a common and typical reflex response in of the management of projects. While standardisation of information, training, procedures, and reporting will probably solve some of the problems encountered, it will also create new problems and may even contradict some of the basic principles of CBR. One of the main principles of CBR is that the person with a disability works together with the family trainer and supported the Local Supervisor to design specific, individualised goals to be realised within her own community. These goals and methods may be unorthodox and might not resemble methods discussed in the standardised information (e.g. the booklets of the WHO manual) or in the training. For example, in one CBR project a bicycle was provided to the eldest daughter of the family so that she could earn money to ease the financial burden imposed by the mother who had to stay at home to take care of her child with a severe disability. Another project arranged a bus warrant for a man with a disability so that he could go to town and beg in the shopping centre. Whether or not these examples are within the domain of CBR is up for discussion, but they should not be excluded just because they don't fit within the standardised training and reporting system.

The relations of (semi)professional rehabilitation workers with the volunteers, family trainers, and people with disabilities are characteristic of CBR. The projects discussed in this thesis have demonstrated that it is difficult to keep volunteers involved in projects for a longer time. Volunteers are often involved in several community programmes and thus have to divide their limited time between them. They will all have their own reasons for participating. CBR projects demonstrated that volunteers who care for a family member with a disability by themselves seem to be more interested in staying with the project. From experience in the CBR projects in Zimbabwe, we know that younger volunteers drop out easily as they begin looking for a paid job. Working with people who were already functioning within a certain structure (e.g. Village Community Workers), and who do get some payment for their work, seemed more feasible in the Zimbabwean context. 'Reciprocity' has been introduced in this thesis as a way to characterise the relation between stakeholders. The starting point of reciprocity between stakeholders is mutual respect for each other's skills. Once this has been established the stakeholders will meet to discuss and negotiate skills, assistance, information, education, training, and resources they require from each other. Inequalities in information, skills, etcetera are intrinsic to the rehabilitation process, and they are reflected in the 'power' differences between the involved stakeholders. In the discussion about CBR, people with disabilities have sometimes been portrayed, or more or less caricatured, as powerless, fully dependent on the whims and fancies of rehabilitation workers, and excluded from any decision-making in the rehabilitation programme. From this point of view, any rehabilitation worker would be prone to (ab)using her power at the cost of people with disabilities. Consequently, in this view, empowering people with disabilities is only possible if rehabilitation workers at all levels are disempowered and all decisions about rehabilitation, at the individual as well as the collective level, are made by people with disabilities themselves. The slogan 'nothing about us, without us' seems to be largely misused to support this point of view. However, such a radical point of view threatens the 'reciprocity' which is believed to be essential

in the CBR process. Practicing 'reciprocity' between stakeholders will include sharing information, applying specialised skills, reallocating resources, etc. This type of relationship would result in a redirection of power, and not a complete shift of power in which the empowerment of some results in the disempowerment of others.

Selectivity

The WHO-CBR model has been accused of focussing only on people with physical disabilities. However, this is not the case because the manual includes packages that pertain to people with development problems, learning problems, and people with strange behaviour. In the 1994 definition, it is clearly stated that *"CBR is a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities"*. In fact, t is in the 'real life' CBR projects that some people with disabilities are included and others are not. There are, for example, projects specifically designed for people with mental retardation (e.g. the Zimcare project in Zimbabwe), for people with polio and other movement disorders (e.g. Malawi Against Polio), for people with vision disorders, for people with hearing and speech problems, or for people affected by leprosy. CBR projects can also focus specifically on children (e.g. 3D projects in Jamaica (M. J. Thorburn, 1990a, 1990b)), adults (Socio Economic Rehabilitation projects (ILEP, 1999)), or the elderly. Even projects intended to assist all people with disabilities, such as the CBR pilot projects in Zimbabwe, are biased towards people with physical disabilities because rehabilitation workers feel (because of training and experience) more confident in dealing with these type of disabilities and will refer people with other disabilities to specialised services. It can be concluded that the WHO-CBR model is in essence a comprehensive model, but it is the CBR projects that are often selective. Parallel to this discussion of comprehensive versus selective projects, it is important to note that Disabled People Organisations strive for a cross-disability orientation (comprehensive) at the national level, but the organisations that form it are often impairment-specific (selective). It is at the community and district level that these impairment-specific organisations are generally most active. Also, people with disabilities noticeably appear to form groups on the basis of a shared condition (e.g. a vision disorder, being a parent of a child with mental retardation) more than on the basis of an issue (e.g. the right to go to school).

The people with disabilities that engage in rehabilitation projects are from different backgrounds and they are involved for different reasons. A cross-disability approach does not necessarily mean that the needs of all of the people with disabilities will be equally addressed. Seddon, Laing & Daines (2001) argue that there is a social hierarchy of impairment and that Disabled People Organisations are not a very good representation of people with disabilities. According to them, white middleclass male paraplegics dominate the disability movement in Britain, and in countries affected by war and civil strife, it will be the war veterans who are privileged.

So far, the discussion has been limited to conflicts within the rehabilitation process. Naturally, conflicts will also arise between CBR and other community development projects (e.g. small business schemes, women development projects). It is common, and easy, to say that people in different development projects should work together, but, in reality, these projects often rely on the same group of volunteers and have to work with and through the same administration and

political structures. At all levels, rehabilitation projects will have to compete with other projects (in health, education, social welfare, etc.) to be allocated resources (money, training facilities, posts etc.) to start and continue CBR projects. The HIV/AIDS epidemic creates another source of conflict. Projects to prevent HIV infection and to take care of people affected by the virus draw heavily on the available resources. Most importantly, AIDS/HIV is a disabling condition that affects all of the stakeholders in the rehabilitation process. Working in Tanzania, Vanneste (2003) estimated that, in some projects, 30% of the staff members have died. He argues strongly that rehabilitation programmes be involved in the issue of HIV/AIDS. Whilst his approach might be most realistic in the Tanzanian context, it makes rehabilitation subordinate to other, more general, development programmes. In fact, this relates to the discussion on the relevance of a special programme for people with disabilities. However, general development programmes that focus on the 'poorest of the poor' will address many people with disabilities, but they will not be able to provide the expertise and methodology to improve their unequal position within these disadvantaged groups. Also, not all people with disabilities are destitute or affected by HIV/AIDS, and these people should not be denied adequate support. The tension that exists between a specific programme such as CBR, and general development programme will not be eased by merging specific programmes into general programmes. Only a thorough analysis of the needs of a person with a disability will reveal if this person needs specialised support (e.g. rehabilitation) or would benefit best from more general interventions.

Uniqueness

From the beginning, CBR has been criticised as being a medical model, using medical terminology, and seeing people with disabilities as people who need to improve their skills to gain a higher level of independence or to lessen the burden on their caregivers. Early examples of impressive CBR projects with a clear emphasis on education (e.g. the Zimcare programme in Zimbabwe and the CBR projects in Guyana) or on vocational rehabilitation (e.g. the ILO project in Indonesia) have not been able to correct this view. More than a medical model, CBR is an 'individual' model because it focuses on the unique needs of every individual. Although the community (represented by the family trainer and the volunteer) is expected to participate in setting objectives, the objectives will first of all focus on improving the skills and living circumstances of the person with a disability. Objectives aiming at changes in the community are included because these are believed to facilitate the participation of the individual with a disability within the community. This individual model can be contrasted with a 'social' model in which interventions aim at general changes in society. These changes are not connected with the particular needs of an individual, they are expected to benefit a broad group of people that may or may not consist of people with disabilities. In an attempt to influence the public and policy makers, often a well known person with a disability will show that he is not able to enter the town hall, to understand a letter from the municipality, to discern between the symbols on a website, etc. The desired message is always that it is not a personal problem but a problem many people face because not enough thought has been devoted to the accessibility of buildings, information, etc.

The individual and social models use their own vocabulary to express their intentions. In the individual model, rehabilitation workers talk discuss a 'needs-generated' or 'demand-driven'

approach, and in the social model, Disabled People Organisations promote concepts such as 'advocacy' and 'human rights'. It can be argued that a 'needs-generated' approach and promoting the concept of 'advocacy' are simply different elaborations of the principle of 'autonomy' and 'self-responsibility' of people even if they are based on different traditions and ideologies. If CBR is approached as a social model, there is a risk that different stakeholders involved may not be recognised as individual entities with individual skills and authority. This especially applies to the people with disabilities themselves, both the child with a disability who is not going to school and the woman recovering from a stroke who is not getting adequate help, run the risk of being left out of the discussion. Therefore a thoughtless adherence to the 'social model' would be like throwing out the baby with the bathwater. In order for the person with a disability to be able to redefine her unique problem to a social problem, it is most likely that some basic conditions have to be modified first. This is where the person with a disability liaises with some of the other stakeholders in CBR to gain access to information and services and to make use of her own skills to achieve her personal objectives.

8.7 Scenarios

The first 'conflict of interest' discussed ('shifting competency-levels') can be seen as both the cause and the result of the other two 'conflicts of interests' ('selectivity' and 'uniqueness'). These two 'conflicts of interests' are positioned on two axes and form four quadrants that present four approaches to CBR. This is pictured in figure 8.1. These approaches are meant to be possible 'scenarios' for the further development of rehabilitation services for people with disabilities. The perceptions and expectations of the stakeholders will differ in the four scenarios displaying the above-described conflict of interests with regard to the competency-levels of the involved stakeholders.

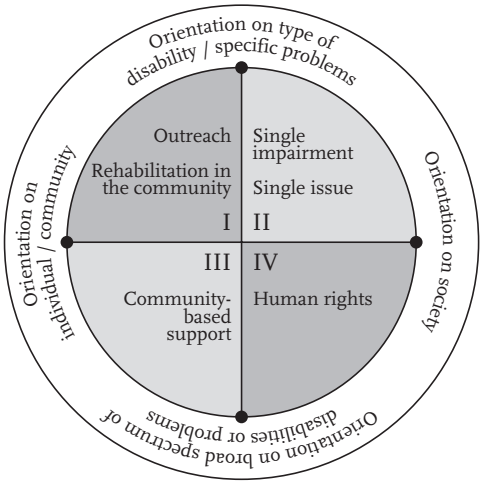


Figure 8.1 Four scenarios for the development of CBR

Quadrant A lists both 'outreach' and 'rehabilitation in the community' as possible approaches for the development of CBR. 'Outreach' refers to activities set up by institutions to offer services to people with disabilities living in the community. The control of these activities, including the use of resources and admission of people with disabilities, lays fully in the hands of the highly qualified professionals in the institutions. This type of community-oriented rehabilitation is an extension of the regular intervention employed by institutions. Sometimes outreach services are set up instead of admitting people with disabilities or asking them to come to outpatient clinics, but they are usually set up to provide often as an aftercare service to people after they have been admitted. 'Rehabilitation in the community' includes all types of community-level, or Community-based rehabilitation activities. Generally, institutions or organisations that are based in the main towns while running different projects in rural areas are responsible for running these activities. Some will support their community work by setting up workshops and resource, referral, and training centres in towns in order to provide services to people with disabilities who have needs that could not be handled in the community. Both 'outreach' and 'rehabilitation in the community' focus on the individual with a disability. As discussed above, this might be obvious for the training offered in and by institutions, but this also applies to training offered at community level. Here, interventions at the community level aim to benefit a known person with a disability. For example, interventions for the child with a physical disability, the rehabilitation worker would discuss the accessibility of the primary school with the teachers, a ramp would be built by a few community members, and a special chair would made by a local craftsmen. Although these interventions might benefit other children with similar problems, they are aimed at a specific child. The WHO-CBR approach fits in this quadrant as do most of the 'real life' CBR projects studied in this thesis.

In quadrant B, rehabilitation focuses on groups of people with comparable conditions or problems. This approach addresses intervention in the context of the social system and it aims to enable people with disabilities to participate and integrate in society. This is the case, for example, when rehabilitation workers educate the community about leprosy. The aim of this education might be to de-stigmatise the people affected by leprosy within the community in addition to informing people about the early signs of the disease. Also, people with the same disabling condition (blindness, cerebral palsy) often form pressure groups to get their specific problems on the agendas of local and national policy makers. Another example of a project that would fit this scenario would be the renovation of a community hall to make it accessible for people with different types of disabilities.

Quadrant C presents a scenario that can be labelled as 'Community-based support' or 'inclusive community'. The essence of this scenario is the elimination of all kinds of barriers (physical, psychological, social) that possibly exclude out community members with disabilities from community activities. Interventions would aim at increasing awareness about these on excluding factors in the community, removing them, and creating a system of support for those who need it. In this approach the individual people with disabilities in the community are known, and their needs are defined at the start of the interventions. An example of a project that fits this scenario is one in which a chicken farm was set up for people who suffered from the effects of a stroke. An income-generating project such as this not only involves many people in the community as they exchange knowledge about feeding and breeding and feeding

chickens, community members are also responsible for acquiring food and building materials, bookkeeping, providing transport to bring the eggs to a market etc. Projects that fit in this scenario will initially be started for a specific group of people, but once the project is fully functioning it will become open for other people with disabilities from that community. This scenario would also promote projects in which people with disabilities work together with able-bodied people in order to earn a living.

The last quadrant, D, positions a comprehensive approach with an orientation that favours the social level. In this scenario the individual needs of a particular person with a disability are no longer recognizable but are perceived to be part of the collective needs of all of the people with disabilities in society. In fact, this scenario replaces the word 'needs' with 'rights' to stress that people with disabilities are entitled to the same rights as all other people. Typical interventions employed in this scenario might be the introduction and amendment of laws to ensure that people with disabilities are entitled to the same rights and can participate in society to the same extent as people who do not have disabilities. This Human Rights approach is very much promoted by the Disabled People Organisations. In their view, many of the problems people with disabilities encounter are not a personal problem but a result of barriers encountered in society. Instead of offering individual rehabilitation and training this person to deal with this barrier, they believe that rehabilitation should be concerned with minimising or removing these barriers in society. To stress their point at the conference on CBR in Helsinki in 2003, the Disabled People Organisations were arguing to remove the R in CBR to instead promote 'Community-based action for the rights of people with disabilities'.

These four scenarios do not necessarily exclude each other, nor do they present a hierarchy or a defined developmental process for CBR. All four scenarios will and can exist simultaneously depending on the organisation, the local situation, the needs identified, the objectives set, etc. However, it is most important to discuss these scenarios when setting up new projects, or to recognise characteristics of a certain scenario when assessing initiatives to improve the lives of people with disabilities and/or their caregivers. It is not only unfair, it is unproductive to research or judge projects with criteria derived from a scenario other than the one the project follows. Academic research is not needed to, for example, discredit CBR projects in quadrant A using a human rights approach (quadrant D) or to object against a single issue approach (quadrant B) using the 'Inclusive community' (quadrant C) point of view. However, good research is needed to develop alternative answers to the needs of a CBR project (as perceived by the different stakeholders involved) and to be able to choose an appropriate scenario to define the project. For already existing projects, systematic research is also required to study the perceived needs, the original choices made, and the objectives, processes, and outcomes of the programme. In addition, a careful study of the benefits and disadvantages of a given scenario can lead to development towards another, possibly more successful, scenario. The extent to which the earlier identified research priorities for CBR (see chapter 2) fit these four scenarios is yet to be seen. For example, working from a human rights approach (scenario D), 'screening' and the 'use of local resources' might not be a priority at all, but 'participation' and the 'impact of affirmative action' on the lives of people with disabilities would be.

These four scenarios have different implications for the involvement, competency-levels and

influences of stakeholders in the rehabilitation process. Chapter 4 provided a normative or prescriptive framework for the six principal stakeholders involved in CBR. This framework appears to fit best with the first scenario (A). The possession and development of practical skills with which to train the person with a disability and to educate and mentor other stakeholders are essential in this scenario. A further development of this scenario should be based on training and empowering the stakeholders involved (i.e. the four stakeholders in the community: the person with a disability, the family trainer, the Local Supervisor, and the Intermediate Level Supervisor). The second scenario emphasises the promotion of the interests of a certain group of people. The related skills of stakeholders are in the fields of education, social change, etc. Professional rehabilitation workers are generally not trained in these fields. The possession of excellent skills for training people with disabilities, or for instructing and supervising other stakeholders, do not by themselves imply the possession of fine education skills. If stakeholders choose to get involved in rehabilitation projects beyond the second scenario, they first need to develop the appropriate skills. It has been observed that professional rehabilitation workers are often involved in organisations for, or of, people with a specific disorder (e.g. leprosy, cerebral palsy) as a result of their specialised expertise in dealing with people with these conditions. Thus, they may also be reluctant to join pressure groups once they realise that their knowledge does not lay in the field of social change. The key stakeholders in this scenario are the people with disabilities (or their caregivers) who are representing Disabled People Organisations or pressure groups. In the third scenario, a comparable discrepancy in the competency-levels required by the stakeholders can be noted. This scenario focuses on creating awareness about the special needs of people with disabilities, mobilising the community to include people with disabilities in all its activities, and (re)allocating the local resources to make this possible. The people with disabilities, the family trainers, and the Local Supervisor are part of the community, so they might be able to influence community leaders and to present their points of view in informal and formal gatherings and. The Intermediate Level Supervisors are not part of the community (nor are the trainers and planners), and as a result their opportunities to influence the community are limited. In this scenario, the key stakeholders pressing for change will be the people with disabilities, their caregivers, or influential people within the community. The fourth scenario, the Human rights approach, moves even further away from the earlier discussion on the normative competency-levels of the stakeholders involved in CBR projects. At the national level, people with disabilities that have been organised in Disabled People Organisations (often in conjunction with other people and organisations involved in development issues) will act against discrimination and advocate laws to promote equal rights and to guarantee access to information, buildings, services, etc. At the local level, people with disabilities will employ activities to ensure that all people with disabilities exert their rights. In the first scenario, the Intermediate Level Supervisors are very much in control of the project, but, in the other three scenarios the people with disabilities (supported by influential people), are directing the projects. As described earlier, this has weighty consequences for the competency-levels and influences of the other stakeholders, i.e. the professional rehabilitation workers.

As discussed above, these four scenarios are useful in discussing future development of the CBR concept as well as specific CBR projects. Shifting to another scenario may be an attractive

and appropriate way to solve problems encountered in a CBR project. However, if not enough attention is given to the new and different demands that are made on the stakeholders involved, a new scenario will only exist on a superficial level and the discrepancies will only increase the existing problems. This will cause conflicts within and between stakeholders resulting finally in the failure of the project. Moving to another scenario requires a major shift of the roles of the stakeholders involved and can only succeed when the skills and influences have been redefined and the power balance among the stakeholders has been changed accordingly. The discussions regarding inclusion, human rights, etc appear to push for a development of CBR towards a more comprehensive and society-oriented approach to rehabilitation (as in scenario D). Since CBR began without a proper analysis of the needs of people with disabilities and the assistance available, it is interesting that, 25 years later the original concept has been criticised and pushed to develop in another direction without a convincing analysis of the initial claims and prospected methodology. CBR began as an ideology and is now at risk of being replaced by other ideologies before an adequate theoretical foundation of the concept has been formed, discussed, and used as a basis for research.

8.8 Answering the main research question

This thesis presented a model consisting of six intervention levels with corresponding principal stakeholders. Although these intervention levels are highly interdependent, it is possible to describe the specific inputs, processes, and outcomes for each level. As a result of this interdependency, the outcomes of one level will be the inputs for the next intervention level. However, since this thesis began by stating that a 'black box' approach to CBR was unsatisfactory, it still does not help to replace it with six smaller 'black boxes' (one for each intervention level). In order to understand the process of CBR, the roles, interests, and influences of the different stakeholders have been analysed. In doing so, these boxes have been opened and made accessible for research. It has been shown that conflicts exist between the normative (theorised) roles of stakeholders and the actual roles that they fulfil in CBR projects. Ambiguous project objectives and a disparity between the initial training and background of the stakeholders and their expected performance in the project, causes this discrepancy. It has been argued extensively that a CBR project should start by setting clear objectives and identifying stakeholders with the necessary competency-level. Although it is possible to promote this as a bottom-up process, the projects studied in this thesis show that organisations or Ministries generally set the objectives of the project according to their perception of the needs of the stakeholders involved, resources available, etc. However, stakeholders should be enabled and encouraged to modify these objectives to suit their needs and match their competency-levels.

Returning to the main research question presented in paragraphs 1.6 and 8.1 it is concluded that the knowledge and evidence base for CBR is fragmented and weak (i.e. regarding the roles and positions of the stakeholders involved in a CBR project). In chapter 3, the seven 'research priorities' set by the WHO (1988) and adapted by Mitchell (1999b) were used as 'key aspects' to classify the literature on CBR (table 2.2, page 27). These research priorities were very much

derived from the early premises of CBR (figure 1.1, page 6) that were set 25 years ago. With the redevelopment of the original CBR concept, it is expected that these research priorities must also be redefined. For example, sixteen studies about 'screening' that were included in the literature review were published between 1988 and 1997, but this type of research is fully absent in the last time period (1998-2002). On the other hand, in the period 1998-2002, fourteen articles (as many as in the entire ten years before) about 'implementation' (including issues like 'ownership' and 'disability rights') were published. Although these numbers are relatively, they still indicate a shift in the interests of the researchers involved in CBR and/or the publishers.

In further studying the competency-levels of the stakeholders involved in CBR (especially the Rehabilitation Technicians), the use of seven 'research priorities' became highly inconvenient as it was realised that 'stakeholders' could not be approached as a separate 'research priority'. Instead, stakeholders in CBR must be approached as the mediating and decisive factor in the CBR process and in researching the efficacy of screening, change in attitudes, the use of local resources, the implementation of projects, etc. Studies on the so-called 'research priorities' will inevitably lead to recommendations at the level of the different stakeholders as they are the defining factor in the CBR process. Therefore, it is proposed here that any research programme in CBR should directly investigate what people do, and how people work together, to achieve objectives in CBR projects. Possible questions might be: what are the needs of the stakeholders, what are their expectations, how do they perceive their role in the process, do they feel competent, which skills are missing, which stakeholders are missing, how can stakeholders be assisted to increase their competency-levels, what are the expected results for each stakeholder, what is their perception on their role fulfilment, how do they evaluate this, and what type of indicators are required to assess the progress made. In chapter 7, a research study has been presented in which six potential influencing variables (derived from the literature) have been identified that may determine the level of appreciation a specific stakeholder (the caregiver of a child with a disability) has towards a CBR project. This type of research is believed to be more promising and suitable for investigating and influencing the competency-levels of the different stakeholders.

To address the main research question of this thesis it is concluded that a programme theory of CBR is lacking, but it is possible to construct a model for CBR by emphasising the different intervention levels in the CBR process. As such, this model provides good opportunities to analyse the success of the stakeholders and the rehabilitation process. However, while this model fits the original CBR concept, it is apparently less appropriate for other approaches ('scenarios') to CBR. The main difference here is that the original model is based on a professional rehabilitation system complemented with lay rehabilitation workers. The other scenarios either do not have the same structure, or do not work through professional rehabilitation workers. Despite these differences, the rehabilitation process can be adequately described in all scenarios by analysing the stakeholders involved and their relation to other stakeholders. Subsequently, interventions can be designed based on this analysis to adjust and strengthen the position of the stakeholders in the CBR process.

8.9 A new research agenda

Research studies can - and should be - carried out in 'real life' CBR projects. A combination of action research and experimental research will provide valuable information on the CBR process. Combining different research methods will reveal the performance of the different stakeholders as well as providing insight into how they assess their own and others performance in the project. Such research should start with an analysis of the stakeholders (i.e. those living or working in the community. This analysis should include an assessment of their needs (for assistance, information, training, education, resources, etc.) as well as their perception on their initial competency-level and their own role and position in the CBR process). The first step in planning an intervention should be to set the objectives in terms of needs to be met and the skills to be gained by the corresponding stakeholder. Throughout the CBR process, the needs and perceptions of the stakeholders involved will change, and these should be monitored closely. This thesis found that bits and pieces of this type of research have been carried out, but never as part of a comprehensive research project. In order to contribute to the evidence base for CBR, this type of comprehensive research needs to be based on a theoretical model. However, in discussing the four scenarios for CBR projects it became clear that there is not one general model of CBR that is valid for all the possible forms CBR projects can take. For example, the intervention levels of the model presented in chapter 3 will nicely fit scenario A and to a lesser extent B and C, but it does not at all suit scenario D. In fact, not all stakeholders will be equally involved in these four scenarios, and the expectations and competency-levels of those involved will be different. Thus, each scenario requires its own representation on the research agenda to investigate the unique interventions and theoretical ideas on which they are based. In addition, not all types of research conducted in CBR is appropriate for all four scenarios. For example, in a CBR project developing from scenario A to C, it is worth studying how non-disabled community members and people with disabilities perceive their own roles and influences in general community development programmes. There might be a sense of urgency to include people with disabilities in the project, but it is also possible that changes in the project will be most successful if only the most fit or influential community members participate. Here, research should focus on the positions of the different stakeholders in the community in addition to their expectations of the project and of each others contributions. In this example, research about the performance of the professional stakeholders will be less relevant as the problem or questions cannot be defined within the professional rehabilitation system. However, the transfer of skills and knowledge from professional rehabilitation workers to lay people should be researched in projects within scenario A, but this information will be less relevant in scenario D.

This thesis concludes that the CBR research agenda should focus on the stakeholders involved as they are the mediating factor in all types of CBR projects. Because of the different approaches to CBR (here presented as scenarios), this research must be multiform. However, the common element in future research should be the study of the influence of the stakeholders on the CBR process. Any research in CBR projects necessarily includes (at least) two steps: an analysis of the CBR approach ('scenario') chosen or the context in which the project was set up, and an identification of the main stakeholders involved. From here,

expectations on the outcomes and required inputs can be evaluated, and a theory on the process used can be formulated. This strategy will both allow and facilitate context-specific research (relevant within the CBR project) as well as general CBR research (relevant to other CBR projects).

Stakeholders should not be limited to a pre-set or instrumental role in any of the scenarios. The ability to exert influence is seen as a crucial quality for every stakeholder involved in CBR and it is also a prerequisite for cooperating with each other. Research not only describes how stakeholders are functioning within a CBR project, it also has the potential to open doors to allow this functioning to be adapted to the needs of the stakeholders themselves and to the objectives of the project. Of course, influencing the stakeholders can be an explicit aim of the research. However, 'increasing influence' will never imply that professional rehabilitation workers will be less professional or that lay people will be trained to be an expert in rehabilitation. Their influence is within their area of competence, and where the therapist cannot influence the family structure, the family trainer cannot directly influence the overall objectives of the CBR project. "Empowered to differ" means that a CBR approach can be helpful in improving the lives of people with disabilities as a result of these differences in competency-levels and the relations they develop with other stakeholders on the basis of these competency-levels.

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Summary

Twenty-five years of Community-based rehabilitation (CBR) have enriched the field of rehabilitation with numerous rehabilitation programmes for people with disabilities in rural and urban areas in developing countries. CBR has been presented as an alternative or complementary approach to rehabilitation in institutions. In developing countries, these institutions were non-existent, or considered inadequate. In the CBR concept, rehabilitation of people with disabilities takes place in the community and relies explicitly on the involvement of lay people, i.e. family members, volunteers, schoolteachers and village community workers. Despite the ample experience gained with CBR and the evaluations and research studies that have been carried out, the concept and the effectiveness of CBR is still being questioned. This thesis discusses the 'state of the art' of CBR and analyses the findings, pitfalls and shortcomings of current research in CBR, i.e. regarding the competencies and influences of stakeholders involved. It is expected that this approach will contribute to a better conceptualisation of CBR, with the potential to enhance the further development of CBR. In *chapter 1*, definitions of the concepts used in this thesis and the research questions are presented with a brief introduction to the chapters, in which these questions will be answered.

In *chapter 2*, literature on Community-based rehabilitation (CBR) published between 1978 and 2002 is reviewed. There were 128 found that met the criteria set by the author. The articles have been classified according to the methodology used, the key aspects studied, and the country or region to which the study refers. The review showed a still increasing number of publications on CBR, with an average of eight articles per year produced in the last five years. The majority of the studies concern CBR in the Sub-Saharan African region, followed by the next largest number of studies coming from the South Asia and East Asia regions. Only a few articles on CBR in South American countries could be found.
Theory papers and descriptive studies are the most common types of papers in CBR literature. Intervention studies and case reports are relatively rare. No systematic review has yet been carried out although reviews on specific aspects of CBR have become available. The key aspects 'implementation' and 'stakeholders' are relatively well presented but the numbers of articles on 'participation' and 'use of local resources' are noticeably low. Classification of the articles reveals that there is no real focus of research in CBR and therefore the evidence base for CBR is fragmented and incoherent on almost all aspects of CBR.

Chapter 3 explores the initial ideas of CBR and its development over the 25 years of its existence with the aim to reveal and (re)construct the programme theory. It is postulated here that in order to enhance the development of CBR, the underlying concepts should be explored, and insight into the motives of people involved in CBR and the interactions between these people should be obtained. A model of CBR, representing its structure and emphasising the different levels and types of input, interventions, and output, is presented here. This model functions as a theoretical framework in which the different elements of CBR, and the way they interact, are organised in a logical manner with the aim to make these relationships understandable and accessible for intervention, evaluation, and research.

CBR builds on the active involvement of people with disabilities, volunteers, community rehabilitation workers, trainers, planners, and policy makers and can therefore best be viewed as a 'web of interactions' between and among these people. To explore the roles of the people involved in the processes of CBR, a stakeholder analysis is being used and presented in *chapter 4*. In this analysis different stakeholders in CBR have been identified and their position and influence in the process has been anticipated. This type of analysis sheds light on the processes of CBR and, consequently, makes them accessible for research. It also allows developing strategies to get the most effective support from the stakeholders involved. The relevance and efficacy of the different stakeholders will, to a large extent, be defined by the requests and expectations of the other stakeholders involved. In order to assess the stakeholders, a normative framework which includes not only the position and competency of the different stakeholders, but also their decision-making capacities and information needs, was constructed.

The study presented in *chapter 5*, explores and analyses the characteristics of the different stakeholders and their roles in influencing and achieving the objectives of CBR projects. Documentation of CBR projects in Southern Africa has been reviewed. Ten projects out of the more than 30 projects identified have been included in the study. For these ten CBR projects, the stakeholders have been identified, and the objectives of the project have been analysed. Subsequently, the objectives of the project have been related to the interventions made by the different stakeholders involved. In these studies, the role of the Intermediate local supervisor or Rehabilitation Assistant is emphasised. In the projects studied, this cadre played a dominant role in CBR as the most decentralised and community-oriented rehabilitation worker. In fact, CBR, appears to rely completely on the involvement of this type of rehabilitation worker. It is concluded that, with such a strong emphasis on this cadre, and its inclusion in a professional rehabilitation system, the influence of other stakeholders (i.e. the non-professional stakeholders) stays unfocused.

In *chapter 6*, three studies describing selected aspects of the functioning of Rehabilitation Technicians in CBR projects in Zimbabwe are presented. Rehabilitation Technicians were trained in Zimbabwe with the original intent for them to staff rehabilitation services in district and provincial hospitals. The start of eight CBR pilot projects gave them a crucial role in the implementation and running of CBR projects in Zimbabwe. The projects were successful in identifying people who could benefit from rehabilitation and who had had no contact with rehabilitation services before. Half of the people identified had been referred to a hospital or other specialised rehabilitation service. The follow-up of people with disabilities proved to be the bottleneck of the project. Two-thirds of the volunteers that were trained for the survey and home-based training programmes dropped out within two years, and Rehabilitation Technicians did not manage to visit the communities and the people with disabilities on a regular basis. Shortage of manpower, lack of transportation, and unreliable communication were reported by the Rehabilitation Technicians as their main problems in organising home-based training programmes for the people with disabilities and maintaining an effective follow-up routine. It is concluded that the Rehabilitation Technicians are too dependent on the system of health services and the resources provided by the (district) hospitals. Also, they have copied

work processes common in clinical settings and applied them to the CBR setting. It is suggested that Rehabilitation Technicians change their work process in order to become more effective. Instead of providing training directly to the people with disabilities, they should support volunteers in a consistent way, mediate between the person with a disability and specialised health services, and facilitate the development of a common interest between people with disabilities, their caregivers, volunteers, and other community members. In addition, the locus of control of CBR projects should shift towards groups in the community. As such, the CBR process will be controlled at the community level and will be less dependent on professional rehabilitation workers and less prone to logistical problems.

Evaluations of Community-based rehabilitation (CBR) programmes generally focus on quantitative data. To gain insight into the determinants of the outcomes, process oriented data are needed. In *chapter 7* a study to assess the appreciation of Community-based rehabilitation by caregivers of children with a disability is presented. This study was done in the CBR projects in Zimbabwe. Six variables that possibly correlate with the evaluation of CBR by caregivers of children with a disability have been identified from the literature. These variables are (1) traditional beliefs, (2) impact of a child with a disability on the caregiver, (3) community involvement, (4) the perceived ability to teach the child, (5) attitude towards various health services, and (6) expectations for the future of a disabled child.
Seventy-five caregivers were interviewed. The background, perceived abilities to teach, and expectations of the caregivers were very different. The findings of this study suggest that a positive appreciation of CBR is related to a negative attitude towards various health services, and that a positive perception of the ability to teach the child is related to more positive expectations for the future of the child.

Chapter 8 recapitulates the research questions formulated in chapter 1. The premise of this thesis is that the CBR process can only be understood through the stakeholders involved. The adequacy of the interventions is largely determined by the competencies of the stakeholders and how they relate with one another. In the previous chapters, it has been concluded that CBR is not only grafted on clinical services but it also follows the same pyramidal structure, characterised by a strong emphasis on the knowledge and skills of professional rehabilitation workers. In CBR projects the Intermediate Level Supervisors and the lay stakeholders were very much an extension of this professional cadre. This implies that the influence of these stakeholders is more or less on loan from the next stakeholder in the hierarchy, and this influence is therefore regulated by the structure of the project. In fact, stakeholders are hardly able to make decisions that affect their own position in the process, or the direction, of CBR.
'Conflict of interests' between the different stakeholders have influenced the discussion and development of CBR. One 'conflicts of interest' regards the inclusion of people with similar or different disabilities in a project (selective versus comprehensive), and another addresses whether interventions should focus on the individual within her community or within on the society. As a result, the perception of the required competency-levels of the stakeholders involved will differ. These 'conflict of interests' have been adopted into four possible scenarios in CBR. A realistic understanding of the competency-levels of the different stakeholders in each

scenario will aid in empowering these stakeholders. As a result, they will be able to influence their own position and thus make a difference in the overall process. Finally, future research should focus on the influence of the stakeholders involved in CBR. This will not only help us to understand how the different stakeholders perceive, fulfil, and shape their role in part of the process it will also reveal their needs for information, resources, training, and support. An awareness of the these needs will guide the interventions of other stakeholders in addition to the direction of the entire CBR process.

Samenvatting

Vijfentwintig jaar Community-based rehabilitation (CBR) heeft het domein van de revalidatie verrijkt met talloze projecten in rurale en stedelijke gebieden in ontwikkelingslanden. CBR is gepresenteerd als een programma dat in plaats van, of complementair aan, revalidatie in instituten zou kunnen komen. In het CBR concept vindt de revalidatie van mensen met beperkingen plaats in de eigen gemeenschap en is gebaseerd op de betrokkenheid van leken. Daarbij gaat het om familieleden, vrijwilligers, onderwijzers en 'village community workers'. Ondanks de vele ervaringen die zijn opgedaan met CBR en de evaluaties en onderzoeken die er gedaan zijn, roept het concept van CBR nog veel vragen op en worden er kanttekeningen geplaatst bij de effectiviteit van het programma.
In dit proefschrift wordt de huidige stand van zaken rondom CBR besproken en worden de resultaten, de valkuilen en tekortkomingen van het onderzoek naar CBR, en dan in het bijzonder naar de competenties en belangen van de belanghebbenden ('stakeholders'), geanalyseerd. Het is de verwachting dat daarmee wordt bijgedragen aan een betere conceptualisatie van CBR en dat daarmee inzichten ontstaan om de ontwikkeling van CBR te stimuleren. In *hoofdstuk 1* worden de definities gegeven van de concepten die in dit proefschrift worden gebruikt. Daarnaast worden de onderzoeksvragen geformuleerd en volgt een korte introductie op de hoofdstukken waarin deze vragen beantwoord zullen worden.

In *hoofdstuk 2* wordt een overzicht gegeven van de artikelen die tussen 1978 en 2002 over CBR in wetenschappelijke tijdschriften zijn gepubliceerd. In totaal werden 128 artikelen gevonden die voldeden aan de criteria zoals die door de auteur gesteld waren. Deze artikelen zijn geclassificeerd op basis van de methodologie die gebruikt werd, van kern aspecten en naar het land of regio. Het overzicht laat zien dat er ieder jaar meer artikelen over CBR verschijnen. Over de afgelopen vijf jaar waren dat gemiddeld acht artikelen per jaar. Het merendeel van de onderzoeken betreft CBR in landen in 'Afrika ten Zuiden van de Sahara'. Dit wordt gevolgd door onderzoeken in Zuidelijk en Oostelijk Azië. Slechts enkele onderzoeken in Zuid-Amerikaanse landen werden gevonden. Opvallend is dat de artikelen die CBR beschrijven vooral theoretische en beschrijvende studies zijn. Er zijn maar enkele artikelen beschikbaar die gebaseerd zijn op experimentele studies. Een systematisch overzicht van de literatuur is tot nu toe niet beschikbaar. Wel zijn er enkele overzichtsartikelen met betrekking tot specifieke aspecten binnen CBR. De kern aspecten 'implementatie' en 'belanghebbenden' zijn relatief het best onderzocht maar er zijn nauwelijks onderzoeken gepubliceerd over de aspecten 'participatie' en 'lokale middelen'. Het classificeren van de artikelen laat zien dat er geen focus is in het onderzoek en dat bijgevolg de wetenschappelijke basis van bijna alle aspecten van CBR gefragmenteerd en onsamenhangend is.

In *hoofdstuk 3* worden de oorspronkelijke ideeën rondom CBR en de ontwikkeling van het concept in de afgelopen 25 jaar beschreven. De veronderstelling hier is dat de ontwikkeling van CBR alleen versterkt kan worden als de onderliggende theoretische concepten zichtbaar zijn en er inzicht bestaat in de motieven van, en de relaties tussen, de belanghebbenden bij een CBR programma. Om de structuur van CBR, en de verschillende niveaus van interventies, zichtbaar

te maken wordt in dit hoofdstuk een model gepresenteerd waarin de verschillende elementen van CBR, en de wijze waarop ze samenhangen op een logische manier worden weergegeven. Het doel van het model is om die relaties toegankelijk te maken voor interventies, evaluaties en onderzoek.

CBR is gebaseerd op de actieve betrokkenheid van mensen met een beperking, familieleden, vrijwilligers, revalidatiewerkers, trainers, organisatoren en beleidsmakers en kan daarom het beste worden gezien als een 'interactieweb'. In *hoofdstuk 4* is een analyse gemaakt van de positie van de verschillende belanghebbenden in het CBR proces. Met behulp van deze analyse worden de processen in CBR inzichtelijk gemaakt en worden daarmee toegankelijk voor onderzoek. Ook kunnen op basis van die analyse, strategieën worden ontwikkeld om deze belanghebbenden op een effectieve wijze te ondersteunen. Het handelen van deze belanghebbenden zal in belangrijke mate worden bepaald door de vragen en verwachtingen van de andere belanghebbenden. Om een goed beeld te krijgen van al deze belanghebbenden is een normatief kader ontwikkeld. Dit kader omvat naast de functies en competenties van de verschillende belanghebbenden ook hun mogelijkheden om besluiten te nemen ten aanzien van het eigen handelen, het proces en hun informatiebehoeften.

Om de kenmerken van de verschillende belanghebbenden nader te onderzoeken is in *hoofdstuk 5* documentatie over CBR projecten in Zuidelijk Afrika verzameld en besproken. Ruim 30 projecten konden worden benoemd. Van slechts negen projecten was voldoende informatie beschikbaar om een nadere analyse te kunnen maken van de bijdrage van de belanghebbenden aan het realiseren van doelen van de projecten. De documentatie richtte zich vooral op een beschrijving van de belanghebbenden en nauwelijks op de effectiviteit van hun interventies. In enkele studies naar CBR projecten in Zimbabwe en Zuid-Afrika werd de opleiding van de Intermediate Level Supervisors / Rehabilitation Technicians beschreven en is gekeken naar de wijze waarop zij ingezet werden in het CBR proces. Deze revalidatiewerkers waren in deze projecten de meest gedecentraliseerde en gemeenschaps-gerichte revalidatiewerker en de CBR projecten lijken volledig te steunden op de inzet en betrokkenheid van dit type revalidatiewerker. Door de grote nadruk op dit kader, en de invoeging van dit kader in de professionele revalidatiestructuur, blijft het belang van de andere belanghebbenden onderbelicht.

In *hoofdstuk 6* worden drie onderzoeken beschreven die verschillende aspecten van het functioneren van de Rehabilitation Technicians in de CBR projecten in Zimbabwe behandelen. Rehabilitation Technicians zijn oorspronkelijk opgeleid om te werken in de revalidatie-afdelingen van de districts- en provinciale ziekenhuizen. Met de start van de acht CBR projecten kregen zij een belangrijke rol in de implementatie van deze projecten. Het eerste onderzoek liet zien dat de Rehabilitation Technicians veel mensen met beperkingen hebben geïdentificeerd die tot dan toe niet bij hen bekend waren. In het tweede onderzoek werd gevonden dat de helft van de nieuw geïdentificeerde mensen met beperkingen niet adequaat geholpen kon worden in de eigen gemeenschap. Zij werden doorverwezen naar het ziekenhuis of een organisatie voor gespecialiseerde revalidatiezorg. In het derde onderzoek is de follow-up van de mensen met beperkingen onderzocht. Dit blijkt een belangrijk knelpunt te zijn bij de

projecten. Tweederde van de vrijwilligers die werden getraind voor de identificatie en de thuistrainingprogramma's vielen in de eerste twee jaar van het project uit en de Rehabilitation Technicians bleken niet in staat om de gemeenschappen en de mensen met beperkingen regelmatig te bezoeken. De Rehabilitation Technicians gaven aan dat personeelstekorten, vervoersproblemen en onbetrouwbare communicatie de belangrijkste problemen zijn bij het opzetten van een effectieve procedure voor het opvolgen van mensen met beperkingen. Geconcludeerd wordt dat het functioneren van de Rehabilitation Technicians ontoereikend was. Zij waren te zeer afhankelijk van de middelen, logistiek en structuur van de gezondheidszorgvoorzieningen. Om hun functioneren te verbeteren zouden ze hun werkwijze moeten aanpassen. In plaats van het zelf behandelen van mensen met beperkingen kunnen zij hun begeleiding beter richten op een goede afstemming met gespecialiseerde voorzieningen, het ondersteunen van de vrijwilligers en het ontwikkelen van de gemeenschappelijke belangen van mensen met beperkingen, verzorgers, vrijwilligers en andere gemeenschapsleden. Daarbij kan de sturing van het project verschuiven naar groepen binnen die gemeenschap. Daarmee zal CBR meer iets worden van de gemeenschap en minder afhankelijk zijn van de professionele revalidatiewerkers en het gezondheidszorgsysteem.

De evaluaties van CBR projecten worden gekenmerkt door kwantitatieve gegevens over de resultaten van het project. Om inzicht te krijgen in de betekenis van die resultaten zijn echter ook kwalitatieve gegevens over het proces nodig. In *hoofdstuk 7* wordt een onderzoek gepresenteerd naar de waardering van CBR door verzorgers van kinderen met een beperking. Er zijn zes variabelen geïdentificeerd die daarbij mogelijk van belang zijn. Deze variabelen waren (1) geloof in bovennatuurlijke krachten, (2) de invloed van een gehandicapt kind op de verzorgers, (3) betrokkenheid van de gemeenschap, (4) het vertrouwen in de eigen vaardigheid om het kind iets te leren, (5) de houding ten aanzien van de gezondheidszorgvoorzieningen, en (6) de toekomstverwachtingen voor het kind. Het onderzoek werd uitgevoerd in Zimbabwe en er werden 75 verzorgers geïnterviewd. Deze studie laat zien dat er een relatie is tussen de waardering van CBR en de houding ten aanzien van de gezondheidsvoorzieningen en tussen het vertrouwen in de eigen vaardigheid om het kind iets te leren en de toekomstverwachtingen van het kind.

De onderzoeksvragen worden beantwoord in *hoofdstuk 8*. CBR is een complex proces met zes relevante belanghebbenden op drie niveaus. In de literatuurstudie kon de relevantie en effectiviteit van CBR niet overtuigend vastgesteld worden temeer omdat gericht onderzoek op belangrijke aspecten van CBR ontbreekt. De aanname in dit proefschrift is dat CBR alleen goed te begrijpen is als gekeken wordt naar de belanghebbenden. De competentie van deze belanghebbenden en de wijze waarop zij met elkaar omgaan bepalen in belangrijke mate de effectiviteit van de interventies. Eén groep belanghebbenden, de Rehabilitation Technicians, is nader bestudeerd. Hun rol en positie in CBR projecten in Zuidelijk Afrika is gespiegeld met de normatieve rollen en posities. Geconcludeerd wordt dat CBR geënt is op de klinische revalidatie en dezelfde piramide structuur, met een sterke nadruk op kennis en vaardigheden, kent. De Rehabilitation Technicians zijn vooral een uitbreiding van het professionele kader. Daarmee is de invloed van deze Rehabilitation Technicians, net als de andere belanghebbenden, min of meer geleend van de hoger geplaatste belanghebbende en wordt die invloed gereguleerd

door de structuur van het project. In feite zijn de belanghebbenden nauwelijks in staat om beslissingen te nemen die hun positie in het proces of de ontwikkeling van CBR beïnvloeden.

'Belangenconflicten' tussen de belanghebbenden bepalen de discussie rondom en de ontwikkeling van CBR. Eén 'conflict' gaat over het toelaten van mensen met overeenkomstige beperkingen of verschillende beperkingen tot een project (selectief versus algemeen) en een ander 'conflict' spitst zich toe op interventies die gericht zijn op het individu in de gemeenschap of op de maatschappij. Als gevolg daarvan, en tegelijk ook onderliggend aan deze conflicten, verschilt de perceptie op de vereiste competentie van de belanghebbenden. Deze 'belangenconflicten' zijn omgezet in vier scenario's voor CBR. Een realistische benadering van de competenties van de verschillende belanghebbenden in elk scenario kan de positie van die belanghebbende versterken en kan eraan bijdragen dat zij hun positie kunnen beïnvloeden en verschil kunnen maken. Onderzoek zal zich dan ook moeten richten op de invloed van die belanghebbenden. Daarmee wordt het niet alleen mogelijk om te begrijpen hoe de verschillende belanghebbenden hun bijdrage in het proces waarderen, vervullen en vormen maar ook welke behoeften zij hebben. Deze behoeften zijn dan richtinggevend voor de interventies van de andere belanghebbenden en voor de verdere ontwikkeling van CBR.

About the Author

Harry Finkenflügel was born in 1958 in Gendringen, a small rural village in the Eastern part of the Netherlands. He attended secondary school at the Isala college in the nearby village of Silvolde. In 1982 he graduated from the Academy for Physiotherapy 'Jan van Essen' in Amsterdam. He first worked as a physiotherapist in the nursing home 'St. Jacob' in Amsterdam, and later in a residential facility ('Leekerweide') for people with intellectual disabilities in Wognum. He combined this work with further studies at the Faculty of Human Movement Sciences at the Vrije Universiteit of Amsterdam. In 1988 he obtained a Masters degree that including a teaching qualification.

In 1988 he went to Zimbabwe to work for the Ministry of Health on a three-year contract. He was involved in the training of Rehabilitation Technicians and the setting up of eight CBR pilot projects. He also published a few articles about these projects.

Back in the Netherlands he worked in 'de Stolp' in Opmeer which is a day-care centre for children with disabilities before returning to 'Leekerweide' in Wognum as the head of training for the direct care staff.

Concurrently, the Vrije Universiteit employed him for two days a week to teach and to set up a course on Rehabilitation in Developing Countries. Sixteen students attending this course carried out additional research studies under his direction in Zimbabwe, Malawi, Jamaica, and Guyana. Some of their work has been incorporated into this thesis. Together with Ivan Wolffers, he edited the book "The Handicapped Community" wich includes international contributions on experiences in Community-based rehabilitation. From this collaboration the idea of writing a thesis about CBR was born. In 1995 he was involved in the Memisa and CBM evaluation of 'Malawi Against Polio'.

His interest and involvement in education brought him to undertake a Masters degree in Educational Management in 1995. A few months after completion of this degree, he was appointed at a management position in a residential facility providing services for people with intellectual disabilities. This institution, 'SOVAK', in Terheijden, was in the midst of a complicated process to change from a classic institution with all services offered at one place to a decentralised organisation providing care in newly built group homes and sheltered workshops in many villages in the North-West part of Noord-Brabant. This change process, along with major consequences for the people receiving services, their families, and for the direct care staff, was symbolised by the final dismantling of the old institutional buildings and the redevelopment of the institutional grounds in 2002.

In 2002 he accepted a position at the Institute of Health Care Policy and Management of the Erasmus Medical Centre. It is also with their support that this thesis has been completed.

Since the advent of Community-based rehabilitation (CBR) in 1976, many developing countries have conducted CBR projects. CBR has been presented as a relevant and cost-effective way to provide rehabilitation services to people with disabilities. Twenty-five years later it was concluded that, despite the growing amount of literature on the topic, the evidence base for CBR is still fragmented and therefore its effectiveness cannot be sufficiently established. In this thesis, a theoretical model based on the competency levels of the different stakeholders involved in CBR is presented. In addition, an analysis of the stakeholders involved is carried out in order to study the process of CBR. Finally, CBR projects in Southern Africa (i.e. Zimbabwe) have been analysed to determine the influence of these stakeholders on the CBR process.

The stakeholders involved in CBR projects are highly interdependent and rely on each other to achieve programme and individual objectives. However, the interests of these stakeholders conflict on several issues. One of these issues is the need for a specialised competency level versus a broad competency level, and another is their orientation regarding the individual versus society. On the basis of these two issues, this thesis concludes by providing four scenarios for the further development of CBR.

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